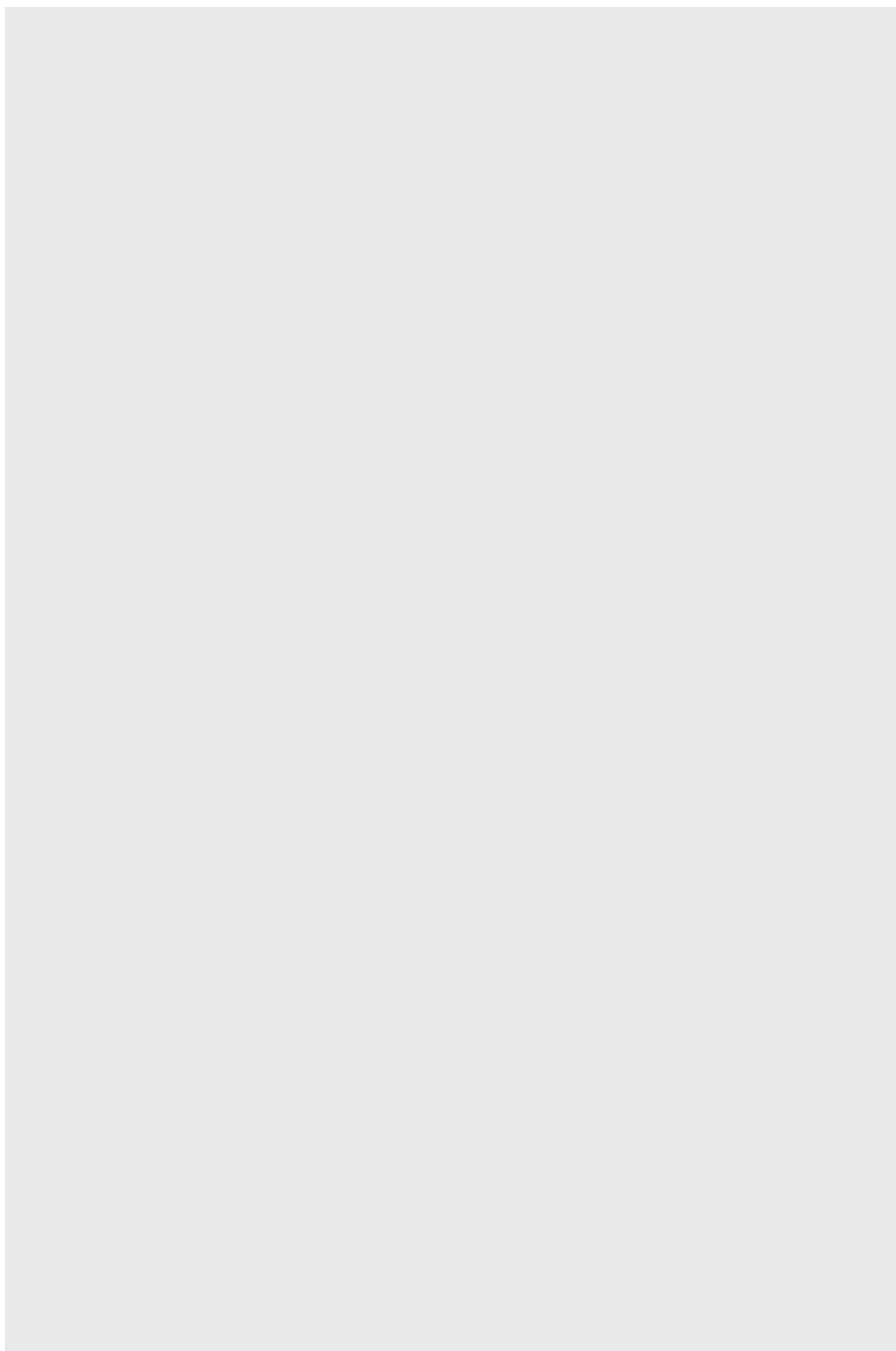


Summary

Policies and guidelines on end-of-life care
decision-making in Dutch health care
institutions

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As end-of-life decision-making is complex, and it is important that it is based on prudent practice, physicians need to have sufficient knowledge (e.g. about regulations, the effects of drugs, and alternative treatment options) and skills (e.g. how to discuss the issue with patient and family) in order to make appropriate decisions. Especially in view of the fact that many physicians do not have regular experience of end-of-life decision-making, both education on end-of-life care in the medical curriculum, and practice guidelines for medical end-of-life decisions could be valuable in supporting physicians in this complex decision-making process. The objectives of this study were subdivided over 2 levels:

I. Institutions

- a) Description of the existence of euthanasia and physician-assisted suicide (EAS) policy statements and practice guidelines for all medical end-of-life decisions in Dutch health care institutions.
- b) Description of the development and dissemination of institutional practice guidelines for medical end-of-life decisions and EAS policy statements to relevant parties in Dutch health care institutions.
- c) Description of the content of institutional EAS guidelines in hospitals and nursing homes, and description of the content of hospital guidelines for do-not-resuscitate (DNR) decisions.
- d) Comparison of the existence, development, dissemination and content of EAS policies and practice guidelines on medical end-of-life decisions in 2005 and in 1994.

II. Physicians and medical students

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

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Methods of research

In order to address the objective of this study the following studies were performed:

a. Questionnaire survey institutions (objective 1 a,b,d)

In the Dutch health care institutions study a questionnaire was sent to the management of all Dutch hospitals, nursing homes, general psychiatric hospitals, institutions for the mentally disabled, and hospices (n=306, response 68%). The questionnaire contained questions about the background characteristics of the institution (e.g. type, size, religious affiliation), the existence of a written EAS policy statement and the content of this policy statement, and the existence of practice guidelines for all medical end-of-life decisions, including the date on which these were formulated or revised.

b. Content analysis of EAS and DNR practice guidelines (objective 1 c)

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

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

The guidelines were analyzed with a checklist. The checklist for EAS guidelines included the following main topics: a) general characteristics of the practice guidelines: format of the document, formulation, and whether the guidelines categorically ruled out the possibility of granting a request from some patients groups (dementia patients, coma patients, incompetent patients) which is categorically stricter than the law;

b) request: involved parties and their roles, conscientious objections and advance euthanasia directives; c) decision-making: due care criteria, involved parties and their roles, refusal of euthanasia requests; d) performance: involved parties and their roles, reporting, and aftercare. The checklist for guidelines for the use of DNR decisions included a) general characteristics of the practice guidelines: definition of DNR, b) policy: general rules for resuscitation, c) decision-making: involved parties and their roles, d) (in)competence: role of proxies/family of incompetent patient, and e) recording/evaluation: evaluation of the advanced decision.

c. Questionnaire survey physicians (objective II a)

All physicians in the departments of internal medicine, pulmonology, neurology, cardiology, pediatrics and anesthesiology in 12 hospitals with at least one set of guidelines for euthanasia received a written questionnaire (n=325, response 52%). The questionnaire consisted of yes/no questions about the physicians awareness, use and perceived supportiveness of the practice guidelines for (1) EAS, (2) DNR decisions, and (3) palliative sedation. They were also asked whether they had been in a situation in which they had to make a decision about end-of life decisions. If they had been in such a situation, they were asked in an open-ended question why the specific guidelines had (not) been supportive for them in daily practice. Their reasons for not reading and not using the practice guidelines were also asked for in an open ended question. One part of the questionnaire consisted of general statements about practice guidelines on medical end-of-life decisions.

d. Questionnaire survey medical students (objective II b)

In the 2006/2007 academic year medical students in their final year at the VU University Medical Center in Amsterdam (n=204, response 68%) attending a mandatory tutorial in their public health clerkship, received a written questionnaire. In the questionnaire they were asked about their opinion regarding the quantity and content of education on end-of-life care. They were asked to score the quantity and content on a 3-point scale (bad, moderate, good), and their opinion about attention to specific topics in the medical curriculum on a 3-point scale (sufficient, insufficient, too much). Questions concerning their knowledge about the euthanasia

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R1 act and the euthanasia definition were also included in the questionnaire, together
R2 with questions on their opinions about specific statements on a 5-point scale
R3 (strongly agree to strongly disagree). Additional questions concerned demographic
R4 characteristics such as age, gender and religious affiliation were also asked.
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R7 **Main findings**

R9 Chapter 2 describes existence of policy statements on euthanasia and physician
R10 assisted suicide (EAS) and practice guidelines for all medical end-of-life decisions in
R11 Dutch health care institutions in 2005, whether the existence of practice guidelines
R12 is related to characteristics of institutions, and compares the existence of policies
R13 in 2005 and 1994. It was found that most institutions (70%) had a written policy
R14 statement concerning EAS, especially hospitals (80%), nursing homes (90%) and
R15 hospices (88%). If an institution had a written policy statement concerning EAS, it was
R16 usually only allowed under specific conditions (75%).The most mentioned specific
R17 condition under which EAS was allowed, was that the judicial requirements for EAS
R18 had to be met, and/or that EAS was performed as described in the institutional
R19 guideline. Institutions mainly had practice guidelines for EAS and do-not-resuscitate
R20 decisions (62% and 63%). A minority of the institutions had practice guidelines on
R21 palliative sedation (27%), alleviation of symptoms with possible life shortening effect
R22 (27%) and withdrawing or withholding treatment on medical grounds (33%). In
R23 general, the percentage of institutions with practice guidelines had increased in 2005
R24 compared to 1994, especially in the institutions for the mentally disabled. Religious
R25 affiliation of an institution did not seem to be related to the existence of guidelines.
R26 Larger institutions and institutions with an ethics committee more often had practice
R27 guidelines (Chapter 2).
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R29 Chapter 3 describes the development and dissemination of practice guidelines for
R30 medical end-of-life decisions in Dutch health care institutions. In most health care
R31 institutions, physicians (79%), ethics committees (79%), board of directors (64%)
R32 and nurses (61%) were involved in the development of guidelines. The Euthanasia
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Act and national guidelines were the most frequently reported sources for the development (73% and 71%, respectively) of institutional guidelines on medical end-of-life decisions. Not all institutions disseminated their written EAS policy statements and practice guidelines on medical end-of-life decisions to all relevant parties. Systematic dissemination of the EAS policy statement to patients and/or relatives was less common in institutions. Hospitals and nursing homes, most often systematically disseminated their institutional practice guideline for palliative sedation (76% and 85%, respectively) and least often the institutional practice guideline for withholding or withdrawing treatment (69% and 62%, respectively). Dutch physicians who reported the presence of a written guideline for EAS in their institution, felt supported by it in their decision-making after a patient's request for EAS.

Chapter 4 presents the results of a content study of hospital and nursing home guidelines on euthanasia and assisted suicide (EAS) and compares differences between settings and guidelines developed before or after enactment of the Euthanasia law in 2002. 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%).

Chapter 5 describes the content of hospital guidelines regarding do-not resuscitate (DNR) decisions and compares guidelines in 2005 and 1994. Most hospitals described in their guidelines 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 the 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.

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R1 In 2005 almost all hospital guidelines stated that the individual DNR decision should
R2 be recorded in the medical and/or nursing file. Approximately three quarters of the
R3 guidelines described the need to evaluate each individual DNR decision. Between
R4 1994 and 2005, more guidelines recommended that discussions about DNR should
R5 start on admission (14% vs. 32%), and that individual decisions should be evaluated
R6 (64% vs. 76%).
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R8 Chapter 6 describes the awareness, use and supportiveness for physicians of three
R9 practice guidelines on medical end-of-life decisions. Factors that could increase the
R10 awareness of these guidelines were investigated. Most physicians were aware of
R11 the existence of the practice guidelines for euthanasia (75%) and do-not-resuscitate
R12 decisions (63%), and 35% were aware of the existence of the guidelines for palliative
R13 sedation. From the physicians who had read the guidelines and had been in a
R14 situation in which they had to consider a euthanasia request, 88% had used the
R15 guidelines for euthanasia; corresponding figures are 92% for do-not-resuscitate and
R16 100% for palliative sedation. When used, almost all physicians felt the guideline had
R17 been supportive. More positive attitudes towards guidelines and involvement in
R18 guideline development were associated with increased awareness of the presence
R19 of guidelines.
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R21 Chapter 7 describes the opinions and knowledge on education on end-of-life care
R22 in the medical curriculum. Approximately half of the students (55%) considered
R23 the quantity of end-of-life care education in the curriculum moderate; 35% rated
R24 it as good. Half of the students rated the content of end-of-life care education as
R25 moderate (50%); 47% rated it as good. Fourteen percent of the students gave correct
R26 answers to 6 or 7 of the 8 questions about the euthanasia act. Students who took the
R27 elective course "Terminal and Palliative Care," students who had experience with a
R28 patient requesting euthanasia and physician-assisted suicide in their personal lives,
R29 and students with more knowledge of the euthanasia act were more positive about
R30 the quantity of end-of-life care education. Students who completed fewer clerkships
R31 and totally agreed with the statement, "Everyone has the right to decide about
R32 their own life and death" were more positive about the content on end-of-life care
R33 education.
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Chapter 8 presents strengths and limitations of the studies. It also presents the discussion of all findings in a general context. Furthermore implications for the development, content and dissemination of guidelines for medical end-of-life decisions and medical education on end-of-life care are discussed. There is room for improvement on several aspects such as: the presence, dissemination, content and awareness of policies and guidelines and on education on end-of-life care in the medical curriculum. Chapter 8 ends with recommendations for future research.

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