Attitudes & Role of Nurses in Euthanasia and other Medical end-of-Life Decisions

Els Inghelbrecht

Studies presented in this dissertation were supported by grants from:

- The Fund for Scientific Research in Flanders, Belgium (G.0503.05N; FWO 2005-2009)
- The 5th framework programme of the European Commission (QLRT-1999-30859)
- The Institute for the Promotion of Innovation by Science and Technology in Flanders (SBO IWT nr. 050158)

Book design: Els Inghelbrecht
Print: Silhouet, Maldegem

VUBPRESS is an imprint of ASP nv
(Academic and Scientific Publishers nv)
Ravensteingalerij 28
B-1000 Brussels
Tel. ++32 (0)2 289 26 50
Fax ++32 (0)2 289 26 59
E-mail: info@vubpress.be
www.vubpress.be

ISBN 978 90 5487 748 6
NUR 882 / 883 / 897
Legal deposit D/2010/11.161/072

ATTITUDES & ROLE OF NURSES IN EUTHANASIA AND OTHER MEDICAL END-OF-LIFE DECISIONS

Dissertation

Thesis neergelegd ter verkrijging van de graad van Doctor in de Sociale Gezondheidswetenschappen: Medisch-Sociale Wetenschappen

Vrije Universiteit Brussel

Faculteit Geneeskunde en Farmacie

Vakgroep Medische Sociologie

Onderzoeksgroep Zorg rond het Levenseinde

26 mei 2010

ELS INGHELBRECHT

Vrije Universiteit Brussel

RESEARCH GROUP End-of-Life Care

Promoter:	Prof. dr. Luc Deliens
Co-promoters:	Prof. dr. Freddy Mortier
	Prof. dr. Johan Bilsen

Examination committee

President:	Prof. dr. Sigrid Sterckx
Other members:	Prof. dr. Wim Distelmans
	Prof. dr. Reginald Deschepper
	Prof. dr. Judith Rietjens
	Prof. dr. Chris Gastmans
	Prof. dr. Anneke Francke

CONTENT

Chapters 2-8 are based on the following publications

Chapter 2 – Inghelbrecht E, Bilsen J, Mortier F, Deliens L. Nurses' attitudes towards end-of-life decisions in medical practice: a nationwide study in Flanders, Belgium. Palliat Med 2009; 23(7): 649-658.

Chapter 3 – Inghelbrecht E, Bilsen J, Mortier F, Deliens L. Attitudes of nurses towards euthanasia and towards their role in euthanasia: a nationwide study in Flanders, Belgium. Int J Nurs Stud 2009; 46(9): 1209-1218.

Chapter 4 – Inghelbrecht E, Bilsen J, Pereth H, Ramet J, Deliens L. Medical end-of-life decisions: experiences and attitudes of Belgian pediatric intensive care nurses. Am J Crit Care 2009; 18(2): 160-168.

Chapter 5 – Bilsen J, Inghelbrecht E, Chambaere K, Cohen J, Mortier F, Deliens L. Assisted dying under the euthanasia law in Belgium: involvement of nurses by physicians (submitted).

Chapter 6 – Inghelbrecht E, Bilsen J, Mortier F, Deliens L. Factors related to the involvement of nurses in medical end-of-life decisions in Belgium: a death certificate study. Int J Nurs Stud 2009; 45(7): 1022-1031.

Chapter 7 – Inghelbrecht E, Bilsen J, Mortier F, Deliens L. The role of nurses in physician-assisted dying: retrospective study in Belgium. CMAJ 2010 (Early release, published at www.cmaj.ca on May 17, 2010).

Chapter 8 – Inghelbrecht E, Bilsen J, Mortier F, Deliens L. Continuous deep sedation until death in Belgium: a survey among nurses (submitted).

PREFACE AND ACKNOWLEDGEMENTS

Providing patients with high quality end-of-life care is a goal nurses are striving for. They are intensively involved in the provision of end-of-life care and therefore their contributions to and opinions about possible life-shortening end-of-life decisions cannot be ignored. This PhD dissertation has tried to explore this practice from the point of view of the nurses. The nurses who have helped me throughout the whole process deserve my gratitude. They all contributed in the realisation of this work.

Before presenting you with the end product of my PhD-study, I want to thank the people to whom I am indebted.

My PhD could not have been realized without the help of my promoters and co-promotors: Luc Deliens, Freddy Mortier and Johan Bilsen. First of all I want to thank my promoter, Luc. You have given me the opportunity of making my PhD in your Research Group. I very much appreciate the working method you use, in which close supervision is alternated with the freedom to find my own way in research. Thank you for the support and the confidence you have invested in me. Freddy, you have made many constructive comments and provided many valuable insights during the different development phases of this thesis. I have enjoyed working with you. Johan, you were my closest supervisor; you always read and commented on my work thoroughly and have given me the opportunity for personal development through discussions and the occasional casual talk. I have learned much from you, thank you.

It goes without saying that the stimulating environment in which I have worked over the last years had given me many insights and much pleasure. There are many colleagues from the End-of-Life Care Research Group and the Medical Sociology Department who have had a positive influence on my work and motivation and whom I would like to thank. And a special thanks to Koen, you have made work more like pleasure and were always available when (urgent) matters were to be discussed.

Ten slotte wil ik het thuisfront bedanken. Velen onder jullie hebben misschien niet altijd goed begrepen met wat ik al die jaren bezig was, maar toch hebben jullie op een of andere manier bijgedragen aan het afwerken van dit doctoraat. Vooreerst heb ik de betrokkenheid van mijn familie en schoonfamilie zeer gewaardeerd. Ma & Pa, jullie zijn er altijd geweest voor mij en hebben mij veel zorgen en ongemakken ontnomen. Overal waar jullie konden, hebben jullie mij geholpen

waarvoor ik jullie altijd dankbaar zal zijn. Zo ook mijn schoonfamilie, een dikke bedankt om mij te steunen en de goede zorgen zodat ik mijn proefschrift kon afwerken. Ook mijn clubje vriend(inn)en, bedankt voor alle leuke afleidingen.

Tot slot dank ik William en mijn kleine oogappel Guillaume, met wie ik (het plezier in) mijn leven het liefst deel. We hebben het samen al heel druk gehad: werken in het verre Brussel, het bouwen van ons huis, grote verbouwingswerken in de zaak, doctoraat afwerken, de komst van nieuw leven voorbereiden,... Jullie hebben bij het maken van mijn doctoraat mij de leukste afwisseling en afleiding bezorgd. Dankjewel voor alles!

Brussels, May 2010

Part I

Introduction and research questions

Chapter 1

Background

The strong increase of the ageing population, with more chronic diseases, such as cancer, cardiovascular and cerebrovascular disease and dementia, and an associated prolonged period of decline have led to a growing number of people needing care (1;2). Especially near the end of their lives, that care becomes more urgent and demands a dignified, professional and qualitative approach. Physicians, nurses and other professional caregivers provide that care and widely influence how that care is understood and delivered (3).

Technological and biomedical advancements have dramatically improved the potential of medical practice to prolong patients' lives. Curing disease and prolonging life, which are predominant values in medicine, may also lead to a prolongation of life that does not always benefit patients but extends their suffering and compromises their quality of life. Quantity of life, as translated into longer living, does not automatically prevail over quality of life (4). Sometimes life shortening may be an accepted or desired outcome of care (5-10).

Nurses are by the nature of their work concerned with the care of patients near their death, which automatically involves them in complex end-of-life practices (11). Empirical research on the attitudes and role of nurses in those practices has been growing gradually in recent decades. However, nationwide studies on how nurses perceive the practice and how they are involved in it are limited. This hampers the ability to develop an effective policy for the provision of quality end-of-life care and decision-making for patients to which nurses principally contribute (12).

The main research aim of this thesis is to provide a nationwide description of how nurses perceive different medical end-of-life practices, how they see their roles and how they are involved in them. The following paragraphs describe what is understood by medical end-of-life practices, why it is important to study the nurses' attitudes to and role in those practices, what is already known, and where this dissertation hopes to make a contribution.

Medical end-of-life practices

Certain decisions can be made that do not futilely prolong the life of the terminally ill patient and sometimes, hastening death can be an accepted or even appropriate result of end-of-life care. At times patients may experience immense suffering that can not be adequately relieved and may wish not to be fully aware of their dying process. Different kinds of end-of-life decisions may influence the end of a patient's life with each decision having it's own characteristics and indications. It is even likely that different decisions are being made, simultaneous or successively. The different end-of-life practices that are being studied in this dissertation are five kinds of end-of-life decisions with a possible or certain life-shortening effect plus continuous deep sedation in which the life-shortening is questionable and not part of it's definition:

1. *Non-treatment decisions*: the withholding or withdrawing of treatment, taking into account the possibility that death will be hastened or with the explicit intention to hasten death;
2. *Intensified symptom alleviation*: the intensification of alleviation of pain and/or symptoms, taking into account the possibility that death will be hastened or partly with the intention to hasten death;
3. *Euthanasia*: the administration of drugs with the explicit intention to end life at the explicit request of the patient;
4. *Physician-assisted suicide*: the prescription or supply of drugs with the explicit intention to enable the patient to end his or her own life at their explicit request;
5. *Assisted dying without explicit patient request*: the administration of drugs with the explicit intention to end life without an explicit request from the patient;
6. *Continuous deep sedation*: the administration of drugs to keep the patient in deep sedation or coma until death.

In Flanders, Belgium, three nationwide studies have been conducted of which the latest study performed in 2007 showed that in 48% of all deaths, death was preceded by at least one medical end-of-life decision, continuous deep sedation not included (13), mostly involving intensified symptom alleviation (27%) and non-treatment decisions (17%). Euthanasia occurred in 1.9% of all deaths, physician-assisted suicide in 0.07%, and assisted dying without explicit patient request in 1.8%. The number of deaths preceded by one of these end-of-life decisions increased substantially over the years, from 39% in 1998 and 38% in 2001 (14-16), leading to the assumption that end-of-life decision-making has become more common in medical practice. Physicians in Flanders reported using continuous deep sedation in 14.5% of all deaths in 2007, which was substantially higher than in 2001 (8.2%) (17;18), suggesting that continuous deep sedation has also been become a more common practice in end-of-life care. In the Netherlands, wherein studies on end-of-life decisions originated, as in other countries worldwide, studies have also shown that death is often preceded

by end-of-life decisions that possibly hasten death (19-25). Continuous deep sedation was estimated to occur in between 2.5% and 16.5% of all deaths worldwide (26-29). A similar increase of the practice to that in Flanders was found in the Netherlands (30;31) and the UK (32). All these studies point to the importance of medical end-of-life practices nationally and internationally.

Next, end-of-life practices are not only restricted to adult terminally ill patients. Annually, between 400 and 450 children die in Flanders of whom more than half are below the age of one year (33). A study performed in Flanders in 1999-2000, reported that 57% of all deaths of children below the age of one were preceded by an end-of-life decision that possibly or certainly hastened death (34;35). Also among the children who die between the ages of one and 18 years, death is often preceded by such a decision, as a Dutch study has revealed (36). The decision to forgo life-sustaining treatment is frequently made (37-42) and sedatives and analgesics are regularly used (43;44) in dying children, and in about 3% of cases in the Netherlands, the child's death is preceded by the use of drugs explicitly intended to hasten death (45). A recent Flemish study found similar results, which will be published in the near future (46).

Medical end-of-life decision-making falls under the responsibility of the physician who generally makes such decisions together with the patient and his/her relatives. In order to respect the patient's views, three important laws were promulgated in 2002 to guide physicians and other healthcare providers in end-of-life practices, though they are not comprehensive: the law on the rights of the patient (47), the law on palliative care (48), and the euthanasia law (49). Withholding or withdrawing a potential life-prolonging treatment is in Belgium an accepted medical practice at the end of life, as the patient has the right to refuse any further treatment and physicians have the obligation not to perform treatments that are estimated to be medically futile. Next, every patient has the right to adequate pain relief which is guaranteed by the law on patient rights and the law on palliative care. The intensification of pain and/or symptom alleviation is considered as a permissible medical act when it is proportional pain relief, which can have a possible or even foreseen life-shortening effect, pointing to the principle of double effect (50;51). When drugs are given and at the same time death is intended by intensifying the alleviation of pain and symptoms, we come into the grey area of intentionally life-ending acts. Publicly, ethically, professionally and politically debated are those practices wherein the patient is given drugs in order to end life; when occurring at the patient's explicit request, this is euthanasia. This extraordinary, ie not falling under normal medical behaviour, medical act falls under the current euthanasia law, which requires different safeguards to be met. One of these requirements – one of the most fundamental ones – is that the life-ending has to be at the explicit request of the patient. Assisted suicide is not mentioned under the euthanasia law, but, according to the Federal Control and Evaluation Committee Euthanasia to which the physician has to report the life-ending acts by means of drugs explicitly intended to hasten death, is accepted and treated similarly to euthanasia. Ending life by means of drugs without an explicit request by the patient remains illegal.

The Belgian euthanasia law also only applies to adult patients. In recent years, however, whether euthanasia should be allowed for children (12 years and older) has been under debate. Also the possibility to end the life of a terminally ill child who is considered unable to articulate his or her own wishes, is being debated. Finally, continuous deep sedation is considered an option of last resort and can be applied when refractory symptoms cannot be adequately treated. This practice, which is widely used, is medically accepted, but has been much debated as the life-shortening intention of the decision is unclear.

Nurses in medical end-of-life practices

Nurses, as the largest group among the health care professionals, are by the nature of their work involved in end-of-life care. Especially in the last phase of life the focus or goal of treatment is shifted more and more from cure to care of the terminally ill patient (52). Caring for patients is the core business of nurses. This can in the first place be deduced from the legal and deontological assignments of the nursing profession. In general legislation about the nursing profession it is stated that nurses have "to render terminal care and support with the handling of the mourning process" (53), in specific legislation about palliative care that nurses have "to provide palliative care" (54), and in the deontological code for nurses in Belgium that "caring for patients near their death" is one of their fundamental assignments (55). Second, nurses are in caring for their patients legally authorized to perform the technical-nursing activities and to perform the actions that the physician entrust them with, according to legal stipulations (56). Nurses are the physician's closest co-workers in the field in which they perform physician's orders. As for decisions physicians make for a patient nurses have the competence to perform them, sometimes requiring some independence and critical observation. Finally, nurses also provide by the nature of their work, care that covers all life domains (57;58). Nurses are expected to deliver, next to physical care, psychological, social and spiritual care. Generally in Belgium, physicians indicate that in 90% of cases a nurse was involved in the care of a patient in the last three months of life (59;60). As nurses are frequently involved in the care of dying patients and their relatives, they are also likely to be confronted with medical end-of-life practices.

Apart from the specific references to the legal requirements of the nursing profession, as mentioned above, explicit legal guidance of nurses in medical end-of-life practices is lacking, except for some references in the euthanasia law. Physicians are responsible for medical end-of-life decisions and nurses are finding themselves in a labour relation, subordinated to physicians and working mainly under their responsibility. Physicians are severally liable for medical end-of-life practices, but the nurses' liability for their involvement in medical end-of-life practices is not always plainly deducible. Specific for euthanasia, the law allows only physicians to perform euthanasia under strict precautions. Two stipulations in the law do refer to nurses as the law explicitly states that the physician has to discuss the euthanasia request of the patient with nurses involved and everybody who objects on principle is not obliged to cooperate in euthanasia and has the right to withdraw from further care of the patient. A majority of hospitals and one third of the care homes in Flanders have developed written ethical policies concerning euthanasia, in which in a majority of cases nurses are mentioned (61) mostly in the context of their involvement in the decision-making process and in after-care for the patient's relatives. Attention is also frequently given to the conscientious objections of nurses to euthanasia.

Overall, empirical studies, and ethical and political debates about euthanasia and other end-of-life practices, are mostly situated within the medical profession. As described above, the incidence of end-of-life practices has been extensively studied. Physicians have been asked about their end-of-life practices, their attitudes towards euthanasia, continuous deep sedation and other end-of-life decisions, and how they act in making such decisions (62-69).

State of affairs in research on nurses in medical end-of-life practices

A number of studies have explored the attitudes of nurses towards euthanasia, an act illegal in most countries except for the Netherlands, Belgium and, recently, Luxembourg. As most countries have no euthanasia law, some have explored the attitudes of nurses towards possible legalization and whether they think the practice is ethically acceptable. The studies performed in different countries showed a large dispersal: the percentages of nurses who were in favour of legalization ranged from 14% to 78% (70-79), and those who considered euthanasia to be ethically acceptable ranged from 11% to 70% (80-83). Differences are not only found between countries, but also appear to depend on when the study was conducted. Studies among the general public also indicated that there are clear differences in the acceptance of euthanasia among countries (84) and that acceptance also increases over the years (85). Finally, the specialisation wherein nurses work also influences their attitudes, as the above studies included nurses from different specialisations (86;87). For other end-of-life practices, differences in attitudes may also reflect the legal situation, e.g. in Greece, 51% of nurses would not be willing to withhold or withdraw a life-sustaining treatment; some forms of this practice are illegal in Greece (88;89).

The involvement of nurses in euthanasia practice has also been studied, including by questioning physicians. In a review of De Beer et al. (90), six of the 15 studies used physician-only samples and provided only indirect and limited information on the role of nurses. In the Netherlands (91) and Flanders (92), information is available about how often physicians involve nurses in their decision-making and delegate the administering of drugs explicitly intended to hasten the patient's death to them; however, this includes no recent data (1990 for the Netherlands, 1998 for Flanders). Next, some studies have included particular nursing groups in order to gain information about their involvement in euthanasia and other end-of-life practices (93-100). In the United States, Australia, and Japan, some nurses have been asked about whether they were ever confronted with euthanasia requests, whether they were involved in the physician's decision-making or whether they administered the drugs themselves (101-105). In Flanders, a small-scaled study explored palliative care nurses' attitudes and role in euthanasia, pointing to the complexity of attitudes, exploring how nurses see their role, and revealing how they are in fact involved (106;107). The only nationwide study performed among nurses about their involvement in medical end-of-life decisions was found in the Netherlands, where the involvement of nurses in euthanasia (108-110) and in the alleviation of pain and symptoms with a life-shortening intention (111) was explored.
All these relevant studies provide important information about the attitudes and involvement of nurses in euthanasia and other end-of-life decisions, but much remains unknown. Recent figures are lacking, especially since the euthanasia law in Belgium was passed. Most studies are restricted to specific settings (such as palliative and critical care units) or to specific populations of nurses (such as

oncology nurses, intensive care nurses), have small sample sizes, are limited to one particular end-of-life decision (mostly euthanasia or non-treatment decisions in intensive care units), fail to provide a clear definition of what euthanasia means, or provide only a limited aspect of nurses' involvement. Information is lacking on a nationwide level about the degree to which nurses accept euthanasia in a country wherein euthanasia is legally regulated; to what degree they accept other end-of-life practices and how they see their role in these practices. Details are also lacking about the involvement of nurses in euthanasia, and also in other ethically debated end-of-life practices, such as continuous deep sedation. Finally, there is no clear-cut information available about how nurses working in different settings, who have different specialisations and different backgrounds, have also other attitudes to and involvement in end-of-life practices. Baseline information, representative of all nurses caring for terminally ill patients, is needed. Hence, the absence of this basic descriptive information hampers the ability to develop clear guidelines, public policy on nurses' role in end-of-life practices, and good quality of end-of-life care practice.

Finally, in relation to terminally ill children, at present, most end-of-life care for children occurs in paediatric intensive care units (112-115), where nurses make an extensive contribution to the provision of end-of-life care (116;117). Those nurses have to take up the challenge to provide the children and their families with very specialized care. However, little is known about how those nurses see potential life-shortening decisions in a child population, how they are involved in it, and how they experience their involvement.

Research questions

The general objective of this dissertation is to study the attitudes and involvement of Flemish nurses in end-of-life practices. Two parts can be distinguished in the dissertation; the first explores the attitudes of nurses and the second the involvement of nurses. More specifically, the research questions are:

The attitudes of nurses towards end-of-life practices

1. What are the attitudes towards euthanasia and other end-of-life decisions
    a. of nurses who care for patients in general? (*chapters 2 & 3*)
    b. of nurses who care for dying children? (*chapter 4*)
2. How do nurses perceive their role in euthanasia and other end-of-life decisions? (*chapters 2 & 3*)

The involvement of nurses in end-of-life practices

3. How often are nurses consulted by physicians in medical end-of-life decisions? (*chapter 5 & 6*)
4. How are nurses who care for dying children involved in different end-of-life decisions? (*chapter 4*)
5. How are nurses involved throughout the different phases of euthanasia and the use of life-ending drugs without explicit request? (*chapters 5, 6 & 7*)
6. How do nurses who care for dying patients perceive continuous deep sedation and what is their role in it? (*chapter 8*)

Methods

To answer the research questions of this dissertation, three different data sources were used, all with a quantitative and cross-sectional design. The first data source was composed by setting up an original study wherein a large group of nurses were questioned. Those data were enriched with data from a group of death certificate studies that were performed in 1998, 2001 and 2007, and with a study performed among nurses in paediatric intensive care units.

Nu-ELD study

The aim of setting up the Nurses in End-of-Life Decisions study (Nu-ELD study) was to question the nurses themselves about their attitudes towards and involvement in euthanasia and other end-of-life practices. For the two aims different groups of nurses were to be included. For questioning their attitudes, we were interested in the views of nurses who have experience in patient care, as they may in the course of their work be confronted with end-of-life practices. For questioning their involvement, only nurses who have experience in end-of-life practices were included. We therefore created a two-phased study design which is composed of an attitude-study and an involvement-study that were related to each other (**Figure 1**).

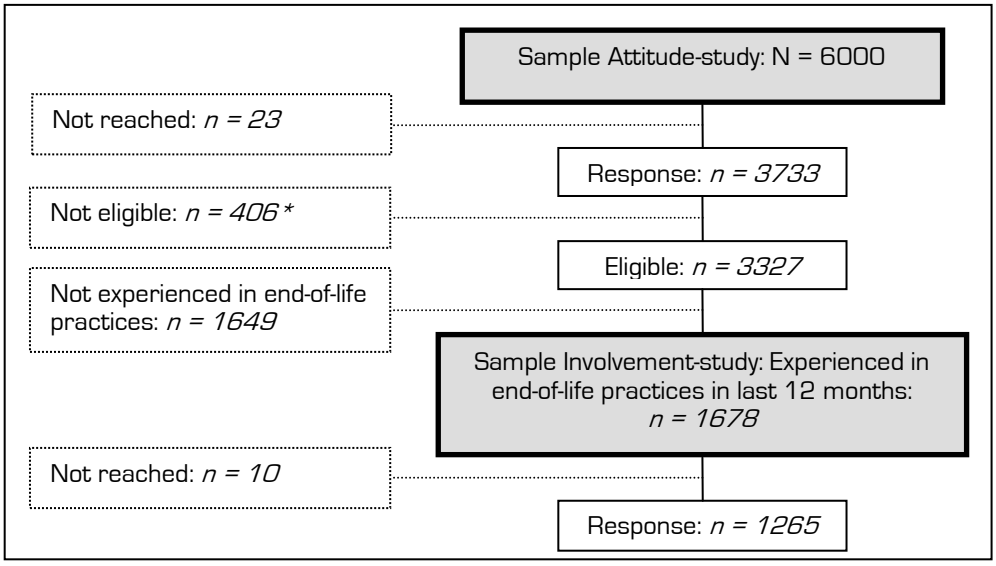


Figure 1. Flow chart of the Nu-ELD study

* In 191 cases the respondent was not a qualified nurse; in 208 cases the nurse had no experiences in patient care; in 2 cases the respondent no longer lived in Flanders; and in 5 cases the respondent was French-speaking.

The Nu-ELD study was performed in the period between August 2007 and February 2008. The sample frame included the nurses who were registered in a nation-wide database that was composed from provincial commissions and educational statistics. In the database, 153,586 nurses were registered of which we excluded the duplicates (n= 1,952) and those who were lacking postal information (n=7,468). We performed our study in Flanders, the northern Dutch-speaking region of Belgium where approximately 60% of the Belgian population lives and therefore excluded those living outside Flanders (n= 51,489) and those who had reported that they were French- or German-speaking (n= 1,295). In order to increase the chances of reaching active nurses, we excluded those aged 56 years or older (n= 16,345). A sample frame of 75,037 remained.

Attitude-study
In the first sub-study, questionnaires were sent to a random sample of 6,000 of the selected 75,037 registered nurses. Response rate was 63% and after exclusion of nurses who had no experience in patient care, a sample of 3,327 nurses remained (**Figure 1**). The nurses were asked for their experience with end-of-life practices and for some personal and work-related characteristics, and were presented with 30 statements about their acceptance of end-of-life practices and their attitudes about their role in it. Agreement with each statement was measured on a 5-point Likert scale.

Involvement-study
In the attitude-study, 1,678 nurses reported having had experience in the last 12 months of caring for patients who received one or more end-of-life decisions (**Figure 1**). Those nurses were sent a questionnaire assessing their experiences and involvement in such decisions based on their recall of the most recent patient cared for whose treatment involved one or more end-of-life decisions. The response rate of this sub-study was 76% and 1,265 questionnaires were returned. All those nurses provided information on the patient they recalled and on the end-of-life decisions made for this patient.

Death Certificate studies
The first death certificate study was performed in 1998; two follow-ups were conducted in 2001 and in 2007. In those studies, a stratified random sample of death certificates was taken, and the physicians attending the deaths, identified from the death certificates, were sent a questionnaire. The sample was taken from all deaths that occurred in Flanders in a given time period. Each death was stratified for the likelihood that an end-of-life decision had preceded it, except for 1998. Details about the deaths in the three studies are presented in **Table 1**. The study aimed at making reliable population estimates of deaths that were preceded by an end-of-life decision and at giving information about the decision-making process. Secondary analyses of previously published data (118-120) were performed focusing on the involvement of nurses in end-of-life decisions.

Table 1. Characteristics of the three death certificate studies

	1998	2001	2007
Total annual deaths – no.	56 354	55 793	54 881
Deaths in study sample – no.	3 999	5 005	6 202
Rate of response to survey – %	48	59	58
Deaths included in analyses – no.	1 925	2 950	3 623

PIC-Nu study

The Paediatric Intensive Care Nurse study (PIC-Nu study) was performed for the whole of Belgium as the annual rate of children dying is rather low and as there are only few units wherein terminally ill children are cared for. In Belgium, seven paediatric intensive care units (PICU) specialize in the care of seriously ill children of which five agreed to cooperate. Questionnaires were distributed to nurses who worked at the five PICUs in 2005. Of the 141 nurses working there, 89 nurses (response: 63%) completed the structured questionnaire. Items in the questionnaire referred to attitudes towards end-of-life decisions in a child population, their experiences with these types of decisions and their involvement in them. In the latter case they were asked to recall the last child in their care who had died after a medical end-of-life decision.

Outline of this dissertation

Following this introduction, the chapters 2-8 of this dissertation are based on articles which have been published, accepted or submitted for publication. All chapters can be read independently.

Part II contains the articles that report on the nurses' attitudes towards end-of-life practices. Chapters 2 and 3 describe the attitudes of Flemish nurses who care for patients in general towards end-of-life decisions and towards their role in those decisions. Chapter 2 includes different kinds of end-of-life decisions, while chapter 3 further examines euthanasia. For both, analyses are made whether or not there are differences in attitudes according to personal and work-related characteristics of the nurses. In chapter 4, the attitudes of paediatric intensive care nurses are presented, in particular how they see euthanasia and other end-of-life decisions for terminally ill children. This chapter also present the results on how those nurses are involved in end-of-life decisions made for terminally ill children.

In part III, we further explore the involvement of nurses in different end-of-life practices. In chapter 5 and 6 results are presented based on the death certificate studies where the incidence of nurses being consulted in end-of-life decisions and those administering drugs in euthanasia and assisted dying without explicit patient request are presented. Chapter 5 shows the results regarding their involvement before and after the passing of the euthanasia law. The focus in chapter 6 is the estimation of nurse involvement, taking into account the characteristics of the patients and the decisions. In chapters 7 and 8 nurses were asked about their involvement in three important and ethically debated end-of-life practices, more specifically in euthanasia and assisted dying without explicit patient request (chapter 7) and in continuous deep sedation (chapter 8). In the latter their perceptions of this end-of-life practice were also analyzed.

The final part of the dissertation (chapter 9) consists of reflections on methodological aspects of the studies, a general discussion of the findings, implications of the findings for health policy and practice, and recommendations for further research.

References

(1) Davies E, Higginson IJ. The solid facts: Palliative Care. Copenhagen: World Health Organization, 2004.
(2) Byock I. Completing the continuum of cancer care: integrating life-prolongation and palliation. CA Cancer J Clin 2000; 50(2):123-132.
(3) Martinson IM, Widmer AG, Portillo CJ. Home health care nursing. 2nd ed. ed. Philadelphia: W.B. Saunders Company, 2002.
(4) Clark D. Between hope and acceptance: the medicalisation of dying. BMJ 2002; 324(7342):905-907.
(5) Deliens L, Mortier F, Bilsen J et al. End-of-life decisions in medical practice in Flanders, Belgium: a nationwide survey. Lancet 2000; 356(9244):1806-1811.
(6) Bilsen J, Cohen J, Chambaere K et al. Medical end-of-life practices under the euthanasia law in Belgium. N Engl J Med 2009; 361(11):1119-1121.
(7) Meier DE, Emmons CA, Wallenstein S, Quill T, Morrison RS, Cassel CK. A national survey of physician-assisted suicide and euthanasia in the United States. N Engl J Med 1998; 338(17):1193-1201.
(8) Kuhse H, Singer P, Baume P, Clark M, Rickard M. End-of-life decisions in Australian medical practice. Med J Aust 1997; 166(4):191-196.
(9) van der Heide A, Onwuteaka-Philipsen BD, Rurup ML et al. End-of-life practices in the Netherlands under the Euthanasia Act. N Engl J Med 2007; 356(19):1957-1965.
(10) Mitchell K, Owens RG. National survey of medical decisions at end of life made by New Zealand general practitioners. BMJ 2003; 327(7408):202-203.
(11) De Beer T, Gastmans C, Dierckx de Casterlé B. Involvement of nurses in euthanasia: a review of the literature. J Med Ethics 2004; 30(5):494-498.
(12) Paice JA, Ferrell BR, Coyle N, Coyne P, Callaway M. Global efforts to improve palliative care: the International End-of-Life Nursing Education Consortium Training Programme. J Adv Nurs 2008; 61(2):173-180.
(13) Bilsen J, Cohen J, Chambaere K et al. Medical end-of-life practices under the euthanasia law in Belgium. N Engl J Med 2009; 361(11):1119-1121.
(14) Bilsen J, Cohen J, Chambaere K et al. Medical end-of-life practices under the euthanasia law in Belgium. N Engl J Med 2009; 361(11):1119-1121.
(15) Deliens L, Mortier F, Bilsen J et al. End-of-life decisions in medical practice in Flanders, Belgium: a nationwide survey. Lancet 2000; 356(9244):1806-1811.
(16) van der Heide A, Deliens L, Faisst K et al. End-of-life decision-making in six European countries: descriptive study. Lancet 2003; 362(9381):345-350.
(17) Chambaere K, Bilsen J, Cohen J et al. Continuous deep sedation until death in Belgium: a nationwide survey. Arch Intern Med 2009; Forthcoming.
(18) Bilsen J, Cohen J, Chambaere K et al. Medical end-of-life practices under the euthanasia law in Belgium. N Engl J Med 2009; 361(11):1119-1121.
(19) van der Heide A, Onwuteaka-Philipsen BD, Rurup ML et al. End-of-life practices in the Netherlands under the Euthanasia Act. N Engl J Med 2007; 356(19):1957-1965.
(20) Seale C. End-of-life decisions in the UK involving medical practitioners. Palliat Med 2009; 23(3):198-204.
(21) van der Heide A, Deliens L, Faisst K et al. End-of-life decision-making in six European countries: descriptive study. Lancet 2003; 362(9381):345-350.
(22) Kuhse H, Singer P, Baume P, Clark M, Rickard M. End-of-life decisions in Australian medical practice. Med J Aust 1997; 166(4):191-196.
(23) Meier DE, Emmons CA, Wallenstein S, Quill T, Morrison RS, Cassel CK. A national survey of physician-assisted suicide and euthanasia in the United States. N Engl J Med 1998; 338(17):1193-1201.
(24) Onwuteaka-Philipsen BD, Fisher S, Cartwright C et al. End-of-life decision making in Europe and Australia: a physician survey. Arch Intern Med 2006; 166(8):921-929.
(25) Mitchell K, Owens RG. National survey of medical decisions at end of life made by New Zealand general practitioners. BMJ 2003; 327(7408):202-203.

(26) Miccinesi G, Rietjens JA, Deliens L et al. Continuous deep sedation: physicians' experiences in six European countries. J Pain Symptom Manage 2006; 31(2):122-129.
(27) Rietjens JA, van der Heide A, Vrakking AM, Onwuteaka-Philipsen BD, van der Maas PJ, van der Wal G. Physician reports of terminal sedation without hydration or nutrition for patients nearing death in the Netherlands. Ann Intern Med 2004; 141(3):178-185.
(28) Seale C. End-of-life decisions in the UK involving medical practitioners. Palliat Med 2009; 23(3):198-204.
(29) van der Heide A, Onwuteaka-Philipsen BD, Rurup ML et al. End-of-life practices in the Netherlands under the Euthanasia Act. N Engl J Med 2007; 356(19):1957-1965.
(30) van der Heide A, Onwuteaka-Philipsen BD, Rurup ML et al. End-of-life practices in the Netherlands under the Euthanasia Act. N Engl J Med 2007; 356(19):1957-1965.
(31) Rietjens J, van Delden JJ, Onwuteaka-Philipsen B, Buiting H, van der Maas PJ, van der Heide A. Continuous deep sedation for patients nearing death in the Netherlands: descriptive study. BMJ 2008; 336(7648):810-813.
(32) Seale C. End-of-life decisions in the UK involving medical practitioners. Palliat Med 2009; 23(3):198-204.
(33) Flemish Ministry of Health. Mortality Statistics Flanders 2000-2008. 2010.
Ref Type: Unpublished Work
(34) Provoost V, Cools F, Mortier F et al. Medical end-of-life decisions in neonates and infants in Flanders. Lancet 2005; 365(9467):1315-1320.
(35) Vrakking AM, van der HA, Provoost V, Bilsen J, van der Wal G, Deliens L. End-of-life decision making in neonates and infants: comparison of The Netherlands and Belgium (Flanders). Acta Paediatr 2007; 96(6):820-824.
(36) Vrakking AM, van der Heide A, Arts WF et al. Medical end-of-life decisions for children in the Netherlands. Arch Pediatr Adolesc Med 2005; 159(9):802-809.
(37) Burns JP, Mitchell C, Outwater KM et al. End-of-life care in the pediatric intensive care unit after the forgoing of life-sustaining treatment. Crit Care Med 2000; 28(8):3060-3066.
(38) Garros D, Rosychuk RJ, Cox PN. Circumstances surrounding end of life in a pediatric intensive care unit. Pediatrics 2003; 112(5):e371-e379.
(39) Devictor DJ, Nguyen DT. Forgoing life-sustaining treatments: how the decision is made in French pediatric intensive care units. Crit Care Med 2001; 29(7):1356-1359.
(40) van der Wal ME, Renfurm LN, van Vught AJ, Gemke RJ. Circumstances of dying in hospitalized children. Eur J Pediatr 1999; 158(7):560-565.
(41) Copnell B. Death in the pediatric ICU: caring for children and families at the end of life. Crit Care Nurs Clin North Am 2005; 17(4):349-360.
(42) Althabe M, Cardigni G, Vassallo JC et al. Dying in the intensive care unit: collaborative multicenter study about forgoing life-sustaining treatment in Argentine pediatric intensive care units. Pediatr Crit Care Med 2003; 4(2):164-169.
(43) Burns JP, Mitchell C, Outwater KM et al. End-of-life care in the pediatric intensive care unit after the forgoing of life-sustaining treatment. Crit Care Med 2000; 28(8):3060-3066.
(44) McCallum DE, Byrne P, Bruera E. How children die in hospital. J Pain Symptom Manage 2000; 20(6):417-423.
(45) Vrakking AM, van der Heide A, Arts WF et al. Medical end-of-life decisions for children in the Netherlands. Arch Pediatr Adolesc Med 2005; 159(9):802-809.
(46) Pousset G, Bilsen J, Cohen J, Chambaere K, Deliens L, Mortier F. Medical end-of-life decisions in children in Flanders, Belgium: a population-based post-mortem survey. Arch Pediatr Adolesc Med 2010; In press.
(47) Belgian Ministry of Justice. Wet betreffende de rechten van de patiënt 22 augustus 2002 (Law concerning patient rights August 22, 2002). 2002022737. 26-9-0002.
(48) Belgian Ministry of Justice. Wet betreffende palliatieve zorg 14 juni 2002 (Law on palliative care June 14, 2002). 2002022868. 26-10-2002.
(49) Belgian Ministry of Justice. Wet betreffende euthanasie 28 mei 2002 (Law on euthanasia May 28, 2002). 2002009590. 22-6-2002.
(50) Sulmasy DP, Pellegrino ED. The rule of double effect: clearing up the double talk. Arch Intern Med 1999; 159(6):545-550.
(51) Magnusson RS. The devil's choice: re-thinking law, ethics, and symptom relief in palliative care. J Law Med Ethics 2006; 34(3):559-569.

(52) Van den Block L, Deschepper R, Bossuyt N et al. Care for patients in the last months of life: the Belgian Sentinel Network Monitoring End-of-Life Care study. Arch Intern Med 2008; 168(16):1747-1754.
(53) Belgian Ministry of Justice. Koninklijk besluit nr. 78 betreffende de uitoefening van de geneeskunst, de verpleegkunde, de paramedische beroepen en de geneeskundige commissies. 10-11-1967.
(54) Belgian Ministry of Justice. Wet betreffende palliatieve zorg 14 juni 2002 (Law on palliative care June 14, 2002). 2002022868. 26-10-2002.
(55) Algemene Unie van Verpleegkundigen in België. Deontologische code voor verpleegkundigen in België. Algemene Unie van Verpleegkundigen in België . 1-11-2004.
(56) Belgian Ministry of Justice. Koninklijk besluit nr. 78 betreffende de uitoefening van de geneeskunst, de verpleegkunde, de paramedische beroepen en de geneeskundige commissies. 10-11-1967.
(57) Payne S, Seymour J, Ingleton C. Palliative care nursing: principles and evidence for practice. Berkshire, England: Open University Press, 2008.
(58) Nolan MT, Mock V. A conceptual framework for end-of-life care: a reconsideration of factors influencing the integrity of the human person. J Prof Nurs 2004; 20(6):351-360.
(59) Van den Block L, Deschepper R, Bossuyt N et al. Care for patients in the last months of life: the Belgian Sentinel Network Monitoring End-of-Life Care study. Arch Intern Med 2008; 168(16):1747-1754.
(60) Van den Block L, Bossuyt N, Van Casteren V, Deliens L. Het sterfbed in België: Resultaten van de SENTI-MELC studie 2005-2006. Brussel: Uitgeverij ASP nv, 2007.
(61) Gastmans C, Lemiengre J, Dierckx de Casterlé B. Role of nurses in institutional ethics policies on euthanasia. J Adv Nurs 2006; 54(1):53-61.
(62) Deliens L, Mortier F, Bilsen J et al. End-of-life decisions in medical practice in Flanders, Belgium: a nationwide survey. Lancet 2000; 356(9244):1806-1811.
(63) van der Heide A, Deliens L, Faisst K et al. End-of-life decision-making in six European countries: descriptive study. Lancet 2003; 362(9381):345-350.
(64) Bilsen J, Cohen J, Chambaere K et al. Medical end-of-life practices under the euthanasia law in Belgium. N Engl J Med 2009; 361(11):1119-1121.
(65) Miccinesi G, Fischer S, Paci E et al. Physicians' attitudes towards end-of-life decisions: a comparison between seven countries. Soc Sci Med 2005; 60(9):1961-1974.
(66) Van den Block L. End-of-life care and medical decision-making in the last phase of life. Vrije Universiteit Brussel, 2008.
(67) Chambaere K, Bilsen J, Cohen J, Raman E, Deliens L. Differences in performance of euthanasia and continuous deep sedation by French- and dutch-speaking physicians in brussels, belgium. J Pain Symptom Manage 2010; 39(2):e5-e7.
(68) Pardon K, Deschepper R, Vander Stichele R, Bernheim J, Mortier F, Deliens L. Preferences of advanced lung cancer patients for patient-centred information and decision-making: a prospective multicentre study in 13 hospitals in Belgium. Patient Educ Couns 2009; 77(3):421-429.
(69) Meeussen K, Van den Block L, Bossuyt N et al. GPs' awareness of patients' preference for place of death. Br J Gen Pract 2009; 59(566):665-670.
(70) Kuhse H, Singer P. Voluntary euthanasia and the nurse: an Australian survey. Int J Nurs Stud 1993; 30(4):311-322.
(71) Young A, Volker D, Rieger PT, Thorpe DM. Oncology nurses' attitudes regarding voluntary, physician-assisted dying for competent, terminally ill patients. Oncol Nurs Forum 1993; 20(3):445-451.
(72) Musgrave CF, Margalith I, Goldsmidt L. Israeli oncology and nononcology nurses' attitudes toward physician-assisted dying: a comparison study. Oncol Nurs Forum 2001; 28(1):50-57.
(73) Asai A, Ohnishi M, Nagata SK, Tanida N, Yamazaki Y. Doctors' and nurses' attitudes towards and experiences of voluntary euthanasia: survey of members of the Japanese Association of Palliative Medicine. J Med Ethics 2001; 27(5):324-33
(74) Tanida N, Asai A, Ohnishi M et al. Voluntary active euthanasia and the nurse: a comparison of Japanese and Australian nurses. Nurs Ethics 2002; 9(3):313-322.
(75) Cartwright CM, Williams GM, Parker MH, Steinberg MA. Does being against euthanasia legislation equate to being anti-euthanasia? Intern Med J 2006; 36(4):256-259.

(76) Bendiane MK, Galinier A, Favre R et al. French district nurses' opinions towards euthanasia, involvement in end-of-life care and nurse patient relationship: a national phone survey. J Med Ethics 2007; 33(12):708-711.
(77) Kumas G, Öztunç G, Alparslan Z. Intensive care unit nurses' opinions about euthanasia. Nurs Ethics 2007; 14(5):637-650.
(78) Tepehan S, Ozkara E, Yavuz MF. Attitudes to euthanasia in ICUs and other hospital departments. Nurs Ethics 2009; 16(3):319-327.
(79) Bendiane MK, Bouhnik AD, Galinier A, Favre R, Obadia Y, Peretti-Watel P. French hospital nurses' opinion about euthanasia and physician-assisted suicide: a national phone survey. J Med Ethics 2009; 35(4):238-244.
(80) Tepehan S, Ozkara E, Yavuz MF. Attitudes to euthanasia in ICUs and other hospital departments. Nurs Ethics 2009; 16(3):319-327.
(81) Asai A, Ohnishi M, Nagata SK, Tanida N, Yamazaki Y. Doctors' and nurses' attitudes towards and experiences of voluntary euthanasia: survey of members of the Japanese Association of Palliative Medicine. J Med Ethics 2001; 27(5):324-330.
(82) Musgrave CF, Soudry I. An exploratory pilot study of nurse-midwives' attitudes toward active euthanasia and abortion. Int J Nurs Stud 2000; 37(6):505-512.
(83) Tanida N, Asai A, Ohnishi M et al. Voluntary active euthanasia and the nurse: a comparison of Japanese and Australian nurses. Nurs Ethics 2002; 9(3):313-322.
(84) Cohen J, Marcoux I, Bilsen J, Deboosere P, van der Wal G, Deliens L. European public acceptance of euthanasia: socio-demographic and cultural factors associated with the acceptance of euthanasia in 33 European countries. Soc Sci Med 2006; 63(3):743-756.
(85) Cohen J, Marcoux I, Bilsen J, Deboosere P, van der Wal G, Deliens L. Trends in acceptance of euthanasia among the general public in 12 European countries (1981-1999). Eur J Public Health 2006; 16(6):663-669.
(86) Holt J. Nurses' attitudes to euthanasia: the influence of empirical studies and methodological concerns on nursing practice. Nurs Philos 2008; 9(4):257-272.
(87) Tepehan S, Ozkara E, Yavuz MF. Attitudes to euthanasia in ICUs and other hospital departments. Nurs Ethics 2009; 16(3):319-327.
(88) Patelarou E, Vardavas CI, Fioraki I, Alegakis T, Dafermou M, Ntzilepi P. Euthanasia in Greece: Greek nurses' involvement and beliefs. Int J Palliat Nurs 2009; 15(5):242-248.
(89) Voultsos P, Njau SN, Vlachou M. The issue of euthanasia in Greece from a legal viewpoint. J Forensic Leg Med 2010; 17(3):131-136.
(90) De Beer T, Gastmans C, Dierckx de Casterlé B. Involvement of nurses in euthanasia: a review of the literature. J Med Ethics 2004; 30(5):494-498.
(91) Muller MT, Pijnenborg L, Onwuteaka-Philipsen BD, van der Wal G, van Eijk JT. The role of the nurse in active euthanasia and physician-assisted suicide. J Adv Nurs 1997; 26(2):424-430.
(92) Bilsen JJ, Vander Stichele RH, Mortier F, Deliens L. Involvement of nurses in physician-assisted dying. J Adv Nurs 2004; 47(6):583-591.
(93) Asch DA. The role of critical care nurses in euthanasia and assisted suicide. N Engl J Med 1996; 334(21):1374-1379.
(94) Kuhse H, Singer P. Voluntary euthanasia and the nurse: an Australian survey. Int J Nurs Stud 1993; 30(4):311-322.
(95) Tanida N, Asai A, Ohnishi M et al. Voluntary active euthanasia and the nurse: a comparison of Japanese and Australian nurses. Nurs Ethics 2002; 9(3):313-322.
(96) Matzo ML, Emanual EJ. Oncology nurses' practices of assisted suicide and patient-requested euthanasia. Oncol Nurs Forum 1997; 24(10):1725-1732.
(97) Ganzini L, Harvath TA, Jackson A, Goy ER, Miller LL, Delorit MA. Experiences of Oregon nurses and social workers with hospice patients who requested assistance with suicide. N Engl J Med 2002; 347(8):582-588.
(98) Morita T, Miyashita M, Kimura R, Adachi I, Shima Y. Emotional burden of nurses in palliative sedation therapy. Palliat Med 2004; 18(6):550-557.
(99) Rietjens JA, Hauser J, van der Heide A, Emanuel L. Having a difficult time leaving: experiences and attitudes of nurses with palliative sedation. Palliat Med 2007; 21(7):643-649.
(100) Benbenishty J, Ganz FD, Lippert A et al. Nurse involvement in end-of-life decision making: the ETHICUS Study. Intensive Care Med 2006; 32(1):129-132.
(101) Asch DA. The role of critical care nurses in euthanasia and assisted suicide. N Engl J Med 1996; 334(21):1374-1379.

(102) Kuhse H, Singer P. Voluntary euthanasia and the nurse: an Australian survey. Int J Nurs Stud 1993; 30(4):311-322.
(103) Tanida N, Asai A, Ohnishi M et al. Voluntary active euthanasia and the nurse: a comparison of Japanese and Australian nurses. Nurs Ethics 2002; 9(3):313-322.
(104) Matzo ML, Emanual EJ. Oncology nurses' practices of assisted suicide and patient-requested euthanasia. Oncol Nurs Forum 1997; 24(10):1725-1732.
(105) Ganzini L, Harvath TA, Jackson A, Goy ER, Miller LL, Delorit MA. Experiences of Oregon nurses and social workers with hospice patients who requested assistance with suicide. N Engl J Med 2002; 347(8):582-588.
(106) De Bal N, Dierckx de Casterlé B, De Beer T, Gastmans C. Involvement of nurses in caring for patients requesting euthanasia in Flanders (Belgium): A qualitative study. Int J Nurs Stud 2006; 43(5):589-599.
(107) Denier Y, Dierckx de Casterlé B, De Bal N, Gastmans C. Involvement of nurses in the euthanasia care process in Flanders (Belgium): an exploration of two perspectives. J Pal Care 2010; 25(4):264-274.
(108) van Bruchem-van de Scheur GG, van der Arend AJ, Huijer Abu-Saad H, van Wijmen FC, Spreeuwenberg C, Ter Meulen RH. Euthanasia and assisted suicide in Dutch hospitals: the role of nurses. J Clin Nurs 2008; 17(12):1618-1626.
(109) van Bruchem-van de Scheur GG, van der Arend AJ, Huijer Abu-Saad H, Spreeuwenberg C, van Wijmen FC, Ter Meulen RH. The role of nurses in euthanasia and physician-assisted suicide in The Netherlands. J Med Ethics 2008; 34(4):254-258.
(110) van Bruchem-van de Scheur GG, van der Arend AJ, Spreeuwenberg C, Huijer Abu-Saad H, Ter Meulen RH. Euthanasia and physician-assisted suicide in the Dutch homecare sector: the role of the district nurse. J Adv Nurs 2007; 58(1):44-52.
(111) van Bruchem-van de Scheur GA, van der Arend AJ, Huijer Abu-Saad H, van Wijmen FC, Spreeuwenberg C, Ter Meulen RH. Alleviation of pain and symptoms with a life-shortening intention. Nurs Ethics 2008; 15(5):682-695.
(112) Althabe M, Cardigni G, Vassallo JC et al. Dying in the intensive care unit: collaborative multicenter study about forgoing life-sustaining treatment in Argentine pediatric intensive care units. Pediatr Crit Care Med 2003; 4(2):164-169.
(113) Copnell B. Death in the pediatric ICU: caring for children and families at the end of life. Crit Care Nurs Clin North Am 2005; 17(4):349-360.
(114) Carter BS, Howenstein M, Gilmer MJ, Throop P, France D, Whitlock JA. Circumstances surrounding the deaths of hospitalized children: opportunities for pediatric palliative care. Pediatrics 2004; 114(3):e361-e366.
(115) Crain N, Dalton H, Slonim A. End-of-life care for children: bridging the gaps. Crit Care Med 2001; 29(3):695-696.
(116) Mekechuk J. Moral distress in the pediatric intensive care unit: the impact on pediatric nurses. Int J Health Care Qual Assur Inc Leadersh Health Serv 2006; 19(4-5):i-vi.
(117) Harbaugh BL, Tomlinson PS, Kirschbaum M. Parents' perceptions of nurses' caregiving behaviors in the pediatric intensive care unit. Issues Compr Pediatr Nurs 2004; 27(3):163-178.
(118) van der Heide A, Deliens L, Faisst K et al. End-of-life decision-making in six European countries: descriptive study. Lancet 2003; 362(9381):345-350.
(119) Bilsen J, Cohen J, Chambaere K et al. Medical end-of-life practices under the euthanasia law in Belgium. N Engl J Med 2009; 361(11):1119-1121.
(120) Deliens L, Mortier F, Bilsen J et al. End-of-life decisions in medical practice in Flanders, Belgium: a nationwide survey. Lancet 2000; 356(9244):1806-1811.

Part II

The attitudes of nurses towards end-of-life practices

Chapter 2

Nurses' attitudes towards end-of-life decisions in medical practice: a nationwide study in Flanders, Belgium

Els Inghelbrecht, Johan Bilsen, Freddy Mortier, Luc Deliens

Published in Palliative Medicine 2009; 23(7): 649-658.

Abstract

We investigated on a nationwide level the attitudes of nurses towards end-of-life decisions (ELDs) that may hasten death and towards their role in those decisions. We took a representative random sample of 6000 nurses in Flanders, Belgium. Response rate was 62.5%. Most nurses agreed with the practice of withholding/withdrawing potentially life-prolonging treatments (93%), with decisions to alleviate symptoms with possible life-shortening side effects (96%) and with the practice of euthanasia (92%). Their support for the different decisions existed regardless of whether they had cared for terminally ill patients or not. Most nurses also thought that they have an important role to play especially in the ELD-making process. Nurses' views on their proper role in the administration of drugs in euthanasia and continuous deep sedation showed a large dispersal. Overall, nurses' work setting determines their opinions on nurses' role in ELDs. In conclusion, nurses accept a wide variety of ELDs being practiced with terminally ill patients.

Introduction

Studies performed in different countries have shown that end-of-life decisions (ELDs) with a possible or certain life-shortening effect are common in medical practice (1-5). Death is preceded by at least one ELD in approximately 40% of all deaths (3). Such ELDs include decisions to withhold or withdraw potentially life-sustaining treatments, decisions to alleviate symptoms that may have a life-shortening side effect and decisions to administer drugs explicitly intended to hasten death. The latter, when the drugs are administered on the patient's explicit request, falls under the current euthanasia law in place in Belgium since May 2002 (6). For the other ELDs, neither specific legislation nor specific references to the role of health care professionals exists (7).

As one of the largest groups among health care professionals, nurses play an important role in end-of-life care for patients. The nature of their work involves them directly in the care of terminally ill patients, which includes ELDs (8-12). Patients talk to nurses about their end-of-life wishes and needs. Physicians often consult nurses before making an ELD and sometimes delegate end-of-life acts to them (9;10;12). The substantial involvement of nurses in ELDs raises a lot of questions about their own opinions and attitudes towards this practice and even more towards their role in it. Studies on this topic often concentrate on physicians as they are formally responsible for making ELDs (13). Some studies have explored nurses' attitudes towards ELDs and towards their role therein, but most findings are restricted to particular specialties (e.g. palliative care (14;15) or critical care (16-19)) or to a specific decision (e.g. decisions to withhold or withdraw potentially life-prolonging treatments) (20) or topics (for or against euthanasia legalisation) (18;21;22). Furthermore, little is known about the socio-demographic and work-related characteristics, such as age, religion and nursing specialty (23-25) in relation to their opinions and attitudes.

In this study, we investigate on a nationwide level the attitudes of nurses towards different ELDs and towards their role in those decisions, and aim to detect differences in attitudes between groups of nurses based on their socio-demographic and work-related characteristics.

Methods

Design and study subjects

This study was conducted in 2007 as a nationwide cross sectional questionnaire survey in Flanders, the Dutch speaking part of Belgium where approximately 60% of the population lives. A sample was taken from a federal government database based on statistics from the educational department and from the Provincial Commissions. In Belgium, nurses are registered in the province where they work. Of a total of 153,586 nurses, a sample frame was composed, which included only nurses whose place of residence was known (95% of cases) and living in Flanders. We also included only nurses who were 55 years or younger to enhance the chances of including working nurses. The remaining sample included 75,037 nurses from which a random sample of 6000 respondents was selected. We ascertained by means of a small study whether the database could be applied to the current study which was positively evaluated. Based on their responses to the questionnaire, nurses without any experiences of patient care were also excluded.

Procedure

The study was performed between August and November 2007. The questionnaire was sent with a letter of recommendation signed by the two major nursing professional organisations in Flanders. To improve the response rate, the survey was conducted by the principles of the total design method (26), including three follow-up mailings. The respondents were assured of the confidentiality of the data, and all data were processed anonymously. The study design and questionnaire were approved by the Ethics Committee of the University Hospital of the Vrije Universiteit Brussel.

Survey instrument

The survey instrument was reviewed thoroughly by different experts – an ethicist, a health scientist, a medical sociologist and two nurses, all experienced in end-of-life research – and discussed in a focus group (which included a palliative home care nurse, a psychologist specialised in palliative care and two nurses working in ELD policymaking). Cognitive testing (27) was also conducted with 10 nurses – working in different settings and with or without having experiences with ELDs and/or palliative care – to assess comprehension of the question and answer categories and question wording. The questionnaire consisted of 3½ pages and required approximately 10–15 min to complete. The questionnaire asked for the nurse's experience in patient care and in care for terminally ill patients. Next, three types of ELDs with a possible or certain life-shortening effect were presented:

1) Withholding or withdrawing a potential life-prolonging treatment at the end of life (including artificial food and/or fluid);
2) Intensifying pain and/or symptom alleviation with a possible life-shortening effect (including using medication to bring the patient into a coma until death);
3) Administering or supplying drugs in lethal doses with the explicit intention of hastening the patient's death.

We asked for their experiences with those decisions in the last 12 months and for their acceptance of the decisions and their views on the nurse's role in those decisions in terms of statements. Agreement with each statement was measured on a 5-point Likert scale (strongly disagree, disagree, neutral, agree and strongly agree).We will further use the term euthanasia when it concerns 'the use of drugs in lethal doses on the explicit request of the patient' and the term continuous deep sedation (CDS) when it concerns 'bringing the patient into a coma until death'. Finally, questions on background characteristics such as sex, age, education, employment, work setting and religious identification were asked.

Data analysis

Descriptive statistics were used to describe the socio-demographical and work-related characteristics of the nurses. The five response categories of the statements were transformed into three categories (disagree or strongly disagree, neutral and agree or strongly agree) and percentages were presented. Multivariate logistic regression analyses were used to calculate odds ratios with 95% confidence intervals for the relationships between each statement and the socio-demographical and work-related characteristics of the nurses. The response categories were dichotomised into agreement (agree and strongly agree) versus the other categories (neutral, disagree and strongly disagree). Bonferroni correction procedures were used to adjust for multiple comparisons with significance set at $P < .0033$ ($\alpha = .05/$regression analyses = 15). All analyses were performed using StatXact6 (Cytel Studio, Cambridge, Massachusetts) and SPSS16.0 (SPSS Inc, Chicago, Illinois).

Results

Response and characteristics of nurses

Of the 6000 questionnaires sent, 23 were returned by the post office as undeliverable and 3733 were returned completed (response rate, 62.5%). Age and sex of the response group were compared with the selected sample frame (N = 75,037) wherein a small underrepresentation of male respondents in the respondent group (12%, vs 14% of the sample frame) occurred. Some respondents were excluded because they had never finished their nursing education (191), were living outside Flanders (2), were French-speaking (5) or had never worked in patient care (208). A total study sample included 3327 nurses of whom 88% were female, 63% were Catholic and 51% had a baccalaureate degree (**Table 1**). Fifty-two percent worked in a hospital. Ninety percent had at some time cared for terminally ill patients and 51% had experiences with ELDs in the last 12 months.

Table 1 - Characteristics of the study population (N=3327)*

Socio-demographics	no.	%
Sex		
Men	410	12.3
Women	2914	87.7
Age, y		
Mean ± SD	41.8 ± 7.5	
Median [interquartile range]	43 [36-48]	
Religious affiliation†		
Religious	2796	85.1
Catholic	2055	62.6
Other religious affiliation	58	1.8
Without denomination	683	20.8
Non-religious	489	14.9
Self-reported importance of religion/philosophy of life in their professional attitudes towards ELDs‡		
(totally) not important	1253	38.1
Neutral	958	29.1
(very) important	1082	32.9
Educational level		
Diploma/Associate degree	1506	45.4
Baccalaureate degree	1693	51.1
Master's degree	115	3.5
Work related characteristics and experiences		
Experience as a nurse, y		
Mean ± SD	16.1 ± 8.6	
Median [interquartile range]	16 [9-23]	
Work status in last 12 months		
Full-time	1395	42.1
Part-time	1573	47.4
Unemployed	348	10.5

Table 1 - Characteristics of the study population (N=3327)* "cont."

Work task in last 12 months		
Nurse	2461	74.2
Head nurse	220	6.6
Supervisor of practical training / instructor	89	2.7
Management	113	3.4
Other	45	1.4
None§	389	11.7
Principal work setting in last 12 months		
Hospital	1718	51.8
Nursing home	596	18.0
Home care	449	13.5
Other	196	5.9
None§	357	10.8
Training in palliative care‖		
Yes	836	25.3
No	2468	74.7
Ever cared for terminally ill patients		
Yes	2992	90.4
No	319	9.6
Cared for terminally ill patients in last 12 months		
Yes	1856	56.1
No	1454	43.9
Experiences with ELDs in last 12 months		
Yes	1678	51.0
No	1611	49.0

* Data are presented as numbers and percentages unless otherwise specified. Percentages may not add to 100 due to rounding. Missing data for socio-demographics range from 3 (sex) to 42 (religion/philosophy of life), for work related characteristics and experiences from 10 (work task) to 38 (experiences with ELDs in last 12 months).
† The precise wording of the question was: "what do you consider to be your religion or life-philosophy?" Other religious affiliation was in one fourth Protestants; in one fourth Muslims; and in one fourth Christian-inspired, but not Catholics.
‡ We asked: "How important is your religion/ life-philosophy in your professional attitude towards end-of-life decisions with a possible or certain life-shortening effect?"
§ 'Respondent is unemployed' or 'the function/work setting is not related to nursing'.
‖ Going from the attendance of a workshop to a bachelor after bachelor palliative care.

Attitudes towards ELDs and towards the role of nurses within them

Almost all nurses (96%) agreed that a terminally ill patient, if necessary, should receive drugs to relieve pain and suffering, even if these drugs may hasten the end of the patient's life (**Table 2**). Most nurses (93%) believed that physicians should comply with a patient's request to withhold or withdraw a life-sustaining treatment, and 92% thought that the use of drugs in lethal doses on the explicit request of the patient is acceptable for patients with a terminal illness with extreme uncontrollable pain or other distress. Eighty-three percent of nurses did not agree that in all circumstances physicians should aim at preserving the lives of their patients, even if patients ask for the hastening of the end of their lives. Fifty-seven percent agreed that the administering of drugs to bring the patient into a coma until death is an optimal dying process. Twenty-six percent were neutral on the latter statement.

Table 2 - Attitudes of nurses towards end-of-life decisions and towards their role in end-of-life decisions (N=3327)*

Statements on end-of-life decisions	Disagree or strongly disagree %	Neutral %	Agree or strongly agree %
1. If necessary, a terminally ill patient should receive drugs to relieve pain and suffering, even if these drugs may hasten the end of the patient's life.	0.9	3.0	96.2
2. Physicians should comply with a patient's request to withhold or withdraw a life-sustaining treatment.	1.8	5.4	92.7
3. The use of drugs in lethal doses on the explicit request of the patient is acceptable for patients with a terminal illness with extreme uncontrollable pain or other distress.	3.7	4.7	91.7
4. A person should have the right to decide whether or not to hasten the end of his or her life.	13.0	15.1	71.9
5. Bringing the patient into a coma until death is an optimal dying process, especially if this is the only way to bring the patient's suffering under control.	16.5	26.3	57.2
6. In all circumstances physicians should aim at preserving the lives of their patients, even if patients ask for the hastening of the end of their lives.	82.6	11.8	5.6
Statements on the role of nurses in end-of-life decisions			
1. Because of the central role in the care of the patient, nurses should be involved in the whole process of end-of-life decisions.	2.2	7.7	90.1
2. Whenever it is decided to administer drugs in lethal doses, it has to be discussed with the involved nurses.	4.3	7.1	88.6
3. Whenever it is decided to withhold or withdraw life-sustaining treatment with a patient, it has to be discussed with the involved nurses.	8.5	13.2	78.3
4. Patients talk rather to a nurse about end-of-life decisions than to a physician.	5.6	27.5	66.9
5. Nurses are in a better position to assess patients' end-of-life wishes than physicians are.	13.7	31.8	54.5
6. Physicians are usually prepared to listen to the nurses' opinions about terminally ill patients.	21.4	29.1	49.5
7. Nurses find themselves in a hierarchical subordinate position which makes it difficult to communicate their opinions on proposed end-of-life decisions to the involved physician.	41.2	23.4	35.4
8. I would in no case be prepared to administer the drugs in lethal doses with the explicit intention of ending the patient's life.	42.7	24.8	32.5
9. I would in no case be prepared to administer the drugs to bring the patient into a coma until death.	45.8	28.4	25.9

* Percentages may not add to 100 due to rounding. Missing data for statements on end-of-life decisions range from 7 (statement 1, 2 & 5) to 13 (statement 6) and for nurses' role in end-of-life decisions from 12 (statement 4) to 29 (statement 9).

Nine out of ten nurses agreed that they should be involved in the whole process of ELDs. Respectively 89% and 78% of nurses agreed that decisions to administer drugs in lethal doses and decisions to withhold or withdraw life-sustaining treatments have to be discussed with the nurses involved. Sixty-seven

percent agreed that patients would rather talk to a nurse about ELDs than to a physician. Fifty percent of the nurses believed that physicians are usually prepared to listen to their opinions about terminally ill patients, and 35% agreed with the statement that nurses find themselves in a subordinate position that makes communication with physicians difficult. In cases involving bringing the patient into a coma until death, 46% of nurses would be prepared to administer the drugs themselves as would 43% in cases of administering drugs in lethal doses with the explicit intention of ending the patient's life. Twenty-six and 33% of nurses respectively were not prepared to administer the drugs themselves under any circumstances.

Determinants of attitudes

Multivariate logistic regression analyses showed different characteristics associated with different statements (**Table 3**). Catholic nurses and nurses with another religious affiliation had lower rates of acceptance of euthanasia and of patients having the right to decide on their own death than nonreligious nurses. Those same associations were also found for nurses who considered their religion/philosophy of life important for professional attitudes towards ELDs in comparison to nurses who rated it as neutral or unimportant (especially for Catholic nurses). Compared to hospital nurses, nursing home and home care nurses were less likely to agree on CDS. Nursing home nurses were also less likely to agree on euthanasia than hospital nurses; home care nurses had a higher level of agreement on patients having the right to decide on hastening their own death than did hospital nurses. The position of nurses in the division of labour did not have any influence on their attitudes. The probability of agreeing on withholding/withdrawing life-sustaining treatments was twice as high for nurses who had received training in palliative care as for those who had not. Nurses with ELD experiences had a somewhat higher chance of agreeing on withholding/withdrawing life-sustaining treatments and CDS than nurses who had no such experiences. Finally, whether nurses had cared for terminally ill patients or not did not influence their agreement on the different statements.

Table 3 - Characteristics of nurses supporting statements on end-of-life decisions

		OR [95% CI]*					
		Statement 1 Intensified symptom alleviation	Statement 2 Withholding/ withdrawing life-sustaining treatment	Statement 3 Euthanasia	Statement 4 Patient's right to decide on hastening one's own death	Statement 5 Continuous deep sedation	Statement 6 Physician's duty to preserve life in all circumstances
Age (years)†		ns	ns	ns	ns	1.02 [1.01-1.03]	ns
Sex	Male	ref	ref	ref	ref	ref	ref
	Female	ns	ns	ns	1.54 [1.22-1.95]	ns	ns
Religious affiliation	Catholic	ns	ns	0.28 [0.15-0.52]	0.57 [0.44-0.73]	ns	ns
	Other religious affiliation	ns	ns	0.05 [0.02-0.12]	0.28 [0.16-0.51]	ns	4.17 [1.71-10.21]
	Religious without denomination	ns	ns	ns	ns	ns	ns
	Non-religious	ref	ref	ref	ref	ref	ref
Importance of religion‡	(very) important	ns	ns	0.40 [0.30-0.52]‖	0.77 [0.65-0.92]‖	ns	2.47 [1.79-3.40]‖
	(very) unimportant or neutral	ref	ref	ref	ref	ref	ref
Education	Diploma/Associate degree	ref	ref	ref	ref	ref	ref
	Baccalaureate degree	ns	1.47 [1.09-1.98]	ns	0.74 [0.62-0.88]	ns	ns
	Master's degree	ns	ns	ns	ns	ns	ns
Work task	Nurse	ref	ref	ref	ref	ref	ref
	Head nurse	ns	ns	ns	ns	ns	ns
	Instructor	ns	ns	ns	ns	ns	ns
	Management	ns	ns	ns	ns	ns	ns
	Other or none	ns	ns	ns	ns	ns	ns
Setting	Hospital	ref	ref	ref	ref	ref	ref
	Nursing home	ns	ns	0.57 [0.39-0.83]	ns	0.61 [0.49-0.76]	ns
	Home care	ns	ns	ns	1.64 [1.26-2.15]	0.66 [0.53-0.83]	ns
	Other or none	ns	ns	ns	ns	ns	ns
Training in palliative care	Yes	ns	1.99 [1.35-2.92]	ns	ns	ns	ns
	No	ref	ref	ref	ref	ref	ref
Cared for terminally ill patients	Yes	ns	ns	ns	ns	ns	ns
	No	ref	ref	ref	ref	ref	ref
ELD-experiences§	Yes	ns	1.43 [1.04-1.98]	ns	ns	1.34 [1.12-1.60]	ns
	No	ref	ref	ref	ref	ref	ref

Abbreviations: OR= Odds Ratio; ref= reference category; ns= not significant.

* Odds ratio with 95% confidence interval from multivariate logistic regression models: independent effect of age, sex, religious affiliation, importance of religion, educational level, work task in last 12 months, principal work setting in last 12 months, having had training in palliative care, ever having cared for terminal patients, and having had experiences in last 12 months in caring for patients for whom an end-of-life decision with a possible or certain life-shortening effect had been made. OR is only presented if the independent variable was statistically significant after the Bonferroni correction (multiplied by 15; corrected P = .0033). Separate models for each statement were fitted. For these analyses we compared nurses who (strongly) agreed (1), with the others ['disagree or strongly disagree' or 'neutral' (0)]. The full description of the statements is presented in table 2. No variables were significant for the first statement 'If necessary, a terminally ill patient should receive drugs to relieve pain and suffering, even if these drugs may hasten the end of the patient's life'.

† A problem of multi-collinearity between age and years of experiences as a nurse made us omit the latter.

‡ Self-reported importance of religion/philosophy of life in their professional attitudes towards end-of-life decisions with a possible or certain life-shortening effect.

§ Having had experiences in the last 12 months in caring for patients for whom an end-of-life decision with a possible or certain life-shortening effect had been made. Multi-collinearity occurred between this variable and experiences with caring for terminal patients in the last 12 months. The latter variable has been omitted, as a positive answer on the first question automatically implies a positive answer on the second.

‖ Interaction occurred between religiosity and importance of religion/philosophy of life in their professional attitudes towards end-of-life decisions in the regression for statement 3, 4, and 6. For the three statements, importance of religion/philosophy of life in their attitudes only counts for Catholics: Catholics who rate their religion as important were less agreeing on statement 3 & 4 and more agreeing on statement 6 than Catholics rating their religion as not important.

The most consistent and strongest determinant across the statements dealing with attitudes towards the nurse's role in ELDs was the work setting of the nurses (**Table 4**). In comparison with hospital nurses, home care nurses had a lower likelihood of agreeing that nurses should be involved in the whole ELD process and in discussions about euthanasia. They also agreed less often on requests being posed to nurses rather than to physicians. They had higher chances of not being prepared to administer drugs in cases of euthanasia and CDS. Nursing home nurses agreed more often than hospital nurses that nurses have to be involved in discussions about withholding/withdrawing life-sustaining treatments. They also agreed more often on not being prepared to administer drugs in cases of CDS. Compared with nurses with a basic diploma, nurses with a higher education were more likely to be prepared to administer drugs in cases of euthanasia and CDS. Compared with bedside nurses, head nurses were more often in agreement that physicians are usually prepared to listen to nurses. The likelihood of not being prepared to administer drugs in euthanasia and in CDS was higher among female nurses than among male nurses. Nurses who had at some time cared for terminally ill patients also agreed more often that physicians are usually prepared to listen to nurses. Finally, Catholics, those with another religious affiliation and those who are religious but without denomination who rated their religion as important for their professional attitudes towards ELDs were less likely to be willing to administer drugs in euthanasia and in CDS than nonreligious nurses.

Table 4 - Characteristics of nurses supporting statements on the role of nurses in end-of-life decisions

		OR [95% CI]*							
		Statement 1 Involvement in whole process	Statement 2 Discussion in euthanasia	Statement 3 Discussion in withholding/ withdrawing life-sustaining treatment	Statement 4 Requests rather to nurses	Statement 5 Nurses are in better position to assess	Statement 6 Physicians prepared to listen to nurses	Statement 8 Not prepared to administer drugs in euthanasia	Statement 9 Not prepared to administer drugs in continuous deep sedation
Age (years)†		ns	ns	ns	ns	ns	ns	ns	ns
Sex	Male	ref	ref	ref	ref	ref	ref	ref	ref
	Female	ns	ns	ns	ns	1.50 [1.20-1.88]	ns	1.91 [1.45-2.52]	1.73 [1.27-2.36]
Religious affiliation	Catholic	ns	ns	ns	ns	ns	ns	1.72 [1.34-2.20]	1.85 [1.40-2.45]
	Other religious affiliation	ns	ns	ns	ns	ns	ns	4.26 [2.33-7.80]	ns
	Religious without denomination	ns	ns	ns	ns	ns	ns	ns	ns
	Non-religious	ref	ref	ref	ref	ref	ref	ref	ref
Importance of religion‡	(very) important	ns	ns	ns	ns	ns	1.42 [1.21-1.66]	1.69 [1.43-1.99]‖	1.68 [1.41-1.99]‖
	(very) unimportant or neutral	ref	ref	ref	ref	ref	ref	ref	ref
Degree	Diploma/Associate	ref	ref	ref	ref	ref	ref	ref	ref
	Baccalaureate	ns	1.48 [1.16-1.88]	ns	0.71 [0.60-0.85]	ns	ns	0.73 [0.62-0.87]	0.68 [0.57-0.82]
	Master's	ns	ns	2.84 [1.41-5.73]	ns	ns	ns	ns	0.33 [0.18-0.61]
Work task	Nurse	ref	ref	ref	ref	ref	ref	ref	ref
	Head nurse	ns	ns	ns	ns	ns	1.70 [1.25-2.32]	ns	ns
	Instructor	ns	ns	ns	ns	ns	ns	ns	ns
	Management	ns	ns	ns	ns	ns	ns	ns	ns
	Other or none	ns	ns	ns	ns	ns	1.71 [1.19-2.44]	ns	ns
Setting	Hospital	ref	ref	ref	ref	ref	ref	ref	ref
	Nursing home	ns	ns	1.53 [1.17-2.01]	ns	ns	ns	ns	1.56 [1.22-1.99]
	Home care	0.50 [0.36-0.69]	0.52 [0.39-0.71]	ns	0.56 [0.44-0.71]	ns	ns	1.60 [1.26-2.02]	1.74 [1.35-2.23]
	Other or none	ns	ns	ns	ns	ns	ns	ns	ns
Training in palliative care	Yes	ns	ns	ns	1.42 [1.17-1.72]	ns	ns	ns	ns
	No	ref	ref	ref	ref	ref	ref	ref	ref
Cared for terminally ill patients	Yes	ns	ns	ns	ns	ns	1.80 [1.36-2.37]	ns	ns
	No	ref	ref	ref	ref	ref	ref	ref	ref
ELD-experiences§	Yes	ns	ns	ns	ns	ns	1.50 [1.26-1.79]	ns	0.69 [0.56-0.84]
	No	ref	ref	ref	ref	ref	ref	ref	ref

Abbreviations: OR= Odds Ratio; ref= reference category; ns= not significant.

* Odds ratio with 95% confidence interval from multivariate logistic regression models: independent effect of age, sex, religious affiliation, importance of religion, education, work task in last 12 months, principal work setting in last 12 months, having had training in palliative care, ever having cared for terminal patients, and having had experiences in last 12 months in caring for patients for whom an end-of-life decision with a possible or certain life-shortening effect had been made. OR is only presented if the independent variable was statistically significant after the Bonferroni correction (multiplied by 15; corrected P = .0033). Separate models for each statement were fitted. For these analyses we compared nurses who (strongly) agreed (1), with the others ['disagree or strongly disagree' or 'neutral' (0)]. The full description of the statements is presented in table 2. Only models where associations were significant in the multivariate model are shown in the table. No variables were significant for the 7th statement 'Nurses find themselves in a hierarchical subordinated position which makes it difficult to communicate their opinions on proposed end-of-life decisions to the involved physician'.

† A problem of multi-collinearity between age and years of experiences as a nurse made us omit the latter.

‡ Self-reported importance of religion/philosophy of life in their professional attitudes towards end-of-life decisions with a possible or certain life-shortening effect.

§ Having had experiences in the last 12 months in caring for patients for whom an end-of-life decision with a possible or certain life-shortening effect had been made. Multi-collinearity occurred between this variable and experiences with caring for terminal patients in the last 12 months. The latter variable has been omitted, as a positive answer on the first question automatically implies a positive answer on the second.

‖ Interaction occurred between religiosity and importance of religion/philosophy of life in their professional attitudes towards end-of-life decisions in the regression for statement 8 and 9. For the two statements, differences between religious affiliation only counts for those who rated their religion as important: Catholics, those with another religious affiliation, and those who are religious but without denomination were more agreeing on the statements than non-religious nurses.

Discussion

In this study, nurses' opinions are voiced about ELDs with a possible or certain life-shortening effect and about their role in these decisions. ELDs, including voluntary euthanasia, are commonly accepted by Flemish nurses. Moreover, most nurses think that they have an important role to play especially in the ELD-making process. The nature of the nurse's role in relation to that of the physician elicits more dissent. Nurses' opinions on their proper role in the administration of drugs in euthanasia and CDS also show a large dispersal.

Strengths of the study include the application of an extensive nationwide nurse registration database, which was positively tested on applicability to the present study, a large sample of nurses including only those with patient care experiences, working in different settings, the use of a succinct questionnaire that had been comprehensively tested and the endorsement of the study by authoritative professional nursing groups.

Limitations of the study include the fact that at the time of the study not all provincial commissions had fully updated their database; as a consequence, there might be an underrepresentation of younger nurses. However, younger nurses tend to agree less often than older nurses on one statement only. Furthermore, somewhat fewer men had cooperated in the study in comparison with their representation on the database. However, there were no gender differences in attitudes towards ELDs, though there were for some statements concerning the nurse's role in ELDs. Further, it is known that nurses have difficulties in making categorical decisions in ethically charged situations (24;28), especially when the complexity of the clinical practice is not taken into account. We partly met this shortcoming by using Likert scales with more than dichotomously graded responses (29). However, the full complexity of nurses' attitudes towards ELDs may not have been satisfactorily recorded in the current study.

The first and most important finding is that almost all nurses accept the practice of different types of ELDs. It would be expected that less nurses accept euthanasia than non-treatment or pain alleviation, which is perceived and accepted as medically 'normal'. In a study conducted in Flanders in 2001 wherein physicians were presented the same statements, physicians more often agreed with the option of non-treatment and pain/symptom alleviation than with the option of euthanasia (13;30). In general, nurses exhibit higher levels of support for the different ELDs than physicians do. This difference in views may be related to the fact that physicians are the legally and professionally responsible parties in ELD-making. Nurses appear to emphasise the relief of suffering and thus their caring role. To serve the caring purpose of alleviating suffering seems to be their prime motive, even if this implies the use of lethal drugs. Our results also independently confirm that nurses do not think that preserving life has to be pursued at the expense of the patient's well-being.

CDS has been promoted within Flanders as an ethically superior alternative to euthanasia, especially by opponents of euthanasia (6). Slightly more than half of nurses consider CDS as an optimal dying process, especially if this is the only way to bring the patient's suffering under control. We also found that nurses who have more experiences with CDS consider it more often as an optimal dying process (those with ELD experiences and hospital nurses are more in favour; CDS is mostly carried out in a hospital setting). It was already found that nurses with experiences with CDS consider it to contribute positively to the patient's quality of dying (31;32). Furthermore, as the statement that CDS is 'an optimal dying process' is worded differently from, for example, the statement that states that the use of drugs in lethal doses is 'acceptable', we cannot conclude that less nurses accept CDS in comparison to euthanasia.

The second major finding is that most nurses think that they should be involved in the whole process of ELDs and particularly in discussions about decisions; nurses clearly want to be involved; yet, in practice they may be frequently disappointed as physicians often make decisions without consulting them (3;9;10;33). Furthermore, the hierarchically subordinate position of nurses is, according to one third of them, an obstacle to communication about proposed ELDs. As we found no relevant work or personal factors related to the spread of opinions in this respect, this feeling is more or less evenly distributed over settings and groups of nurses. Their experience of contacts with physicians probably shapes their personal feelings about hierarchical positions. However, their opinions about the willingness of physicians to listen to their views about terminally ill patients are determined by certain personal characteristics. Thus, nurses with a higher education are more likely to believe that physicians are not willing to listen to them. We may wonder whether those nurses have a stronger wish or expect to be heard and that they therefore experience the physician's readiness to listen as unsatisfactory. It may be concluded that more attention should be paid to interdisciplinary consultation, because nurses do have an important bridging function between patient and physician.

In this study, slightly more than 40% of nurses would be prepared to administer drugs in case of CDS and euthanasia. It is remarkable that nurses show equivalent levels of support in the two practices, especially taken into account that the former is considered a nursing task, while the law forbids nurses to perform the latter. Hospital nurses, nurses with a higher education, male nurses and nurses who rate their religion as unimportant are more willing to administer drugs. In a hospital, the delegation of such an important task to nurses is more common (9;10). Nurses with higher education are better educated in medication policy in general and probably more acquainted with those practices. It is also remarkable that similar associated factors were found between the statements dealing with nurses' willingness to administer drugs in CDS and in euthanasia; it could be that nurses see the administering of drugs in both cases as ethically equivalent.

The third and final important finding is that some individual characteristics are independently associated with attitudes towards ELDs and towards the nurse's role in ELDs. Religious affiliation was confirmed as a strong determinant of a nurse's attitude towards euthanasia (24;25). Catholic nurses agree less often with euthanasia. We were also able to demonstrate that this counts for attitudes towards life ending in general. Interestingly, the statements dealing with other ELDs, such as withholding/withdrawing life-sustaining treatments and intensified symptom alleviation, were not related to being religious or not, although those decisions may also hasten the patient's death. Generally, we can wonder to what degree a nurse's religious convictions do have an influence on caring for patients. It would be unethical if a nurse's religious convictions determine his/her caring for patients at the end of life, particularly where these oppose the patient's preferences.

The nurse's work setting is an important determining factor for the statements dealing with nurses' roles in ELDs. It is clear that wishes concerning their levels of involvement differ among groups of nurses according to the setting where they are working. Home care nurses see their role in ELDs very differently from hospital nurses. The literature already indicated that there are important differences in nurses' involvement in ELDs between practices according to the clinical setting (9-11). Clearly, those differences also exist in nurses' attitudes towards their own role perception. We cannot, however, confirm whether clinical practice forms a nurse's attitude or whether a nurse's attitude determines their actual behaviour in practice.

This study provides policy makers and health care professionals with baseline information and a potentially improved framework for understanding practices regarding ELDs. Further studies, however, are needed linking attitudes and practices, especially nurses' experiences with and involvement in ELDs. As nurses want to be involved in ELDs but can be thwarted in their communication with physicians, professional guidance – in educational programs but also in work-related training – could develop their skills and empower them to discuss ELDs within the health care team. Also, the development of standards, particularly with regard to physician–nurse communication, could benefit cooperation between the two professions.

The creation of joint guidelines, taking into account the views of both professions and the specificity of the clinical setting, could facilitate their collaboration in order to provide terminally ill patients a qualitative, respectful and dignified end-of-life care. The extent to which these results can be generalised to other countries needs to be studied but will most probably depend upon the laws, cultural values and professional practices of each country. However, nurses worldwide care for terminally ill patients, are confronted with ELDs and seek to find an ethical response within their own caring profession.

In conclusion, this study shows that nurses strongly agree with the possibility of a wide variety of ELDs being practiced in the care of terminally ill patients. To

nurses, euthanasia and other ELDs are compatible with the alleviation of suffering. Most nurses also think that they have an important role to play especially in the ELD-making process.

Acknowledgements

We thank the thousands of nurses who provided the study data; Jane Ruthven for the English editing; and the Federal Ministry of Public Health, Safety of the Food Chain and Environment, Department Basic Health Care and Emergency Management for access to their federal government database. This study was supported by a grant from the Fund for Scientific Research, Flanders (project FWOAL 336).

References

(1) Meier DE, Emmons CA, Wallenstein S, Quill T, Morrison RS, Cassel CK. A national survey of physician-assisted suicide and euthanasia in the United States. N Engl J Med 1998; 338(17):1193-1201.
(2) Deliens L, Mortier F, Bilsen J, et al. End-of-life decisions in medical practice in Flanders, Belgium: a nationwide survey. Lancet 2000; 356(9244):1806-1811.
(3) van der Heide A, Deliens L, Faisst K, et al. End-of-life decision-making in six European countries: descriptive study. Lancet 2003; 362(9381):345-350.
(4) Kuhse H, Singer P, Baume P, Clark M, Rickard M. End-of-life decisions in Australian medical practice. Med J Aust 1997; 166(4):191-196.
(5) van der Heide A, Onwuteaka-Philipsen BD, Rurup ML, et al. End-of-life practices in the Netherlands under the Euthanasia Act. N Engl J Med 2007; 356(19):1957-1965.
(6) Bilsen J, Vander Stichele R, Broeckaert B, Mortier F, Deliens L. Changes in medical end-of-life practices during the legalization process of euthanasia in Belgium. Soc Sci Med 2007; 65(4):803-808.
(7) Fassier T, Lautrette A, Ciroldi M, Azoulay E. Care at the end of life in critically ill patients: the European perspective. Curr Opin Crit Care 2005; 11(6):616-623.
(8) van Bruchem-van de Scheur G, van der Arend AJ, Abu-Saad HH, van Wijmen FC, Spreeuwenberg C, Ter Meulen RH. Alleviation of pain and symptoms with a life-shortening intention. Nurs Ethics 2008; 15(5):682-695.
(9) Inghelbrecht E, Bilsen J, Mortier F, Deliens L. Factors related to the involvement of nurses in medical end-of-life decisions in Belgium: A death certificate study. Int J Nurs Stud 2008; 45(7):1022-1031.
(10) Bilsen JJ, Vander Stichele RH, Mortier F, Deliens L. Involvement of nurses in physician-assisted dying. J Adv Nurs 2004; 47(6):583-591.
(11) van Bruchem-van de Scheur G, van der Arend AJ, Abu-Saad HH, Spreeuwenberg C, van Wijmen FC, Ter Meulen RH. The role of nurses in euthanasia and physician-assisted suicide in The Netherlands. J Med Ethics 2008; 34(4):254-258.
(12) de Veer AJ, Francke AL, Poortvliet EP. Nurses' involvement in end-of-life decisions. Cancer Nurs 2008; 31(3):222-228.
(13) Miccinesi G, Fischer S, Paci E, et al. Physicians' attitudes towards end-of-life decisions: a comparison between seven countries. Soc Sci Med 2005; 60(9):1961-1974.
(14) Dierckx de Casterlé B, Verpoort C, De Bal N, Gastmans C. Nurses' views on their involvement in euthanasia: a qualitative study in Flanders (Belgium). J Med Ethics 2006; 32(4):187-192.
(15) Asai A, Ohnishi M, Nagata SK, Tanida N, Yamazaki Y. Doctors' and nurses' attitudes towards and experiences of voluntary euthanasia: survey of members of the Japanese Association of Palliative Medicine. J Med Ethics 2001; 27(5):324-330.
(16) DeKeyser GF, Musgrave CF. Israeli critical care nurses' attitudes toward physician-assisted dying. Heart Lung 2006; 35(6):412-422.
(17) Asch DA, DeKay ML. Euthanasia among US critical care nurses. Practices, attitudes, and social and professional correlates. Med Care 1997; 35(9):890-900.
(18) Kumas G, Oztunc G, Nazan AZ. Intensive care unit nurses' opinions about euthanasia. Nurs Ethics 2007; 14(5):637-650.
(19) Sprung CL, Carmel S, Sjokvist P, et al. Attitudes of European physicians, nurses, patients, and families regarding end-of-life decisions: the ETHICATT study. Intensive Care Med 2007; 33(1):104-110.
(20) Hilden HM, Louhiala P, Honkasalo ML, Palo J. Finnish nurses' views on end-of-life discussions and a comparison with physicians' views. Nurs Ethics 2004; 11(2):165-178.
(21) Cartwright CM, Williams GM, Parker MH, Steinberg MA. Does being against euthanasia legislation equate to being anti-euthanasia? Intern Med J 2006; 36(4):256-259.
(22) Bendiane MK, Galinier A, Favre R, et al. French district nurses' opinions towards euthanasia, involvement in end-of-life care and nurse patient relationship: a national phone survey. J Med Ethics 2007; 33(12):708-711.
(23) Ryynanen OP, Myllykangas M, Viren M, Heino H. Attitudes towards euthanasia among physicians, nurses and the general public in Finland. Public Health 2002; 116(6):322-331.

(24) Verpoort C, Gastmans C, De Bal N, Dierckx de Casterle B. Nurses' attitudes to euthanasia: a review of the literature. Nurs Ethics 2004; 11(4):349-365.
(25) Kitchener BA. Nurse characteristics and attitudes to active voluntary euthanasia: a survey in the Australian Capital Territory. J Adv Nurs 1998; 28(1):70-76.
(26) Dillmann DA. The design and administration of mail surveys. Annu Rev Sociol 1991; 17:225-249.
(27) Collins D. Pretesting survey instruments: An overview of cognitive methods. Quality of Life Research 2003; 12(3):229-238.
(28) De Bal N, Gastmans C, Dierckx de Casterlé B. Nurses' involvement in the care of patients requesting euthanasia: a review of the literature. Int J Nurs Stud 2008; 45(4):626-644.
(29) Cohen J, Marcoux I, Bilsen J, Deboosere P, van der Wal G, Deliens L. European public acceptance of euthanasia: socio-demographic and cultural factors associated with the acceptance of euthanasia in 33 European countries. Soc Sci Med 2006; 63(3):743-756.
(30) Onwuteaka-Philipsen BD, Fisher S, Cartwright C, et al. End-of-life decision making in Europe and Australia: a physician survey. Arch Intern Med 2006; 166(8):921-929.
(31) Morita T, Miyashita M, Kimura R, Adachi I, Shima Y. Emotional burden of nurses in palliative sedation therapy. Palliat Med 2004; 18(6):550-557.
(32) Rietjens JA, Hauser J, van der Heide A, Emanuel L. Having a difficult time leaving: experiences and attitudes of nurses with palliative sedation. Palliat Med 2007; 21(7):643-649.
(33) Seale C. Characteristics of end-of-life decisions: survey of UK medical practitioners. Palliat Med 2006; 20(7):653-659.
(34) Materstvedt LJ, Clark D, Ellershaw J, et al. Euthanasia and physician-assisted suicide: a view from an EAPC Ethics Task Force. Palliat Med 2003; 17(2):97-101.

Chapter 3

Attitudes of nurses towards euthanasia and towards their role in euthanasia: a nationwide study in Flanders, Belgium

Els Inghelbrecht, Johan Bilsen, Freddy Mortier, Luc Deliens

Published in International Journal of Nursing Studies 2009; 46(9): 1209-18.

Abstract

Background Nurses have an important role in caring for terminally ill patients. They are also often involved in euthanasia. However, little is known about their attitudes towards it.
Objectives To investigate on a nationwide level nurses' attitudes towards euthanasia and towards their role in euthanasia, and the possible relation with their socio-demographic and work-related characteristics.
Design and participants A cross-sectional design was used. In 2007, a questionnaire was mailed to a random sample of 6000 of the registered nurses in Flanders, Belgium. Response rate was 62.5% and after exclusion of nurses who had no experiences in patient care, a sample of 3321 nurses remained.
Methods Attitudes were attained by means of statements. Logistic regression models were fitted for each statement to determine the relation between socio-demographic and work-related characteristics and nurses' attitudes.
Results Ninety-two percent of nurses accepted euthanasia for terminally ill patients with extreme uncontrollable pain or other distress, 57% accepted using lethal drugs for patients who suffer unbearably and are not capable of making decisions. Seventy percent believed that euthanasia requests would be avoided by the use of optimal palliative care. Ninety percent of nurses thought nurses should be involved in euthanasia decision-making. Although 61% did not agree that administering lethal drugs could be a task nurses are allowed to perform, 43% would be prepared to do so. Religious nurses were less accepting of euthanasia than non-religious nurses. Older nurses believed more in palliative care preventing euthanasia requests and in putting the patient into a coma until death as an alternative to euthanasia. Female and home care nurses were less inclined than male and hospital and nursing home nurses to administer lethal drugs.
Conclusions There is broad support among nurses for euthanasia for terminally ill patients and for their involvement in consultancy in case of euthanasia requests. There is, however, uncertainty about their role in the performance of euthanasia. Guidelines could help to make their role more transparent, taking into account the differences between health care settings.

Introduction

Robust incidence studies have shown that euthanasia, i.e. the administering of drugs with the explicit intention to end the patient's life at the patient's explicit request, occurs in medical practice in Europe, the United States, and Australia (1-5). It is plausible that nurses, as one of the largest groups of health care professionals, whose role frequently encompasses the care of terminally ill patients, will be confronted with requests for euthanasia. Various studies conducted in different countries have not only confirmed this but have also shown that nurses are often explicitly involved in the euthanasia process itself (6;7). About one nurse in four has at some point been confronted with a euthanasia request from at least one patient. Nurses are sometimes consulted by physicians concerning these requests, and occasionally play a role in the performance of euthanasia, ranging from being present during the act to actually administering the lethal medication (8-11). However, differences are observed between subgroups of nurses especially when clinical practice is taken into consideration (12-14). Nurses' substantial involvement in euthanasia raises a lot of questions about their own opinions and attitudes towards this practice and even more towards their role in it. Until now, however, studies investigating these opinions and attitudes are either small scaled or performed in the context of illegality. Furthermore, little is known about the socio-demographic and work-related characteristics, such as age, religion and nursing specialty (15-17) in relation to these opinions and attitudes.

In Belgium, where this study was done, euthanasia is legalized since 2002, allowing euthanasia to be performed only by physicians and under carefully delineated conditions (18). This law mainly addresses the involvement and responsibilities of physicians (19), and does not address the liabilities of nurses, except for two minor stipulations. The first mandates the physician to discuss the patient's euthanasia request in advance with the nursing team in regular contact with the patient (article 3, paragraph 2.4). The second (art. 14) states that nobody – by implication including nurses – can be forced to cooperate in the performance of euthanasia. Also in the debates that preceded euthanasia legalization in Belgium, the voices of nurses were rarely heard (20). Health care institutions have recognised these gaps in the law concerning nurses' role and gave explicit attention to this issue in their written ethics policies and guidelines on euthanasia (21). Also professional nursing organisations in Belgium are working on the legal position of nurses in euthanasia.
Studying nurses' opinions on euthanasia and on their role in it may give additional important information refining and clarifying their found involvement in this practice. As this study is done in one of the two countries with a euthanasia law worldwide, it may also reveal some interactions and implications of possible legislative changes about euthanasia in other countries. More in general, it may contribute to the societal and ethical debate on euthanasia, particularly from a nursing perspective (22), and to the call of nurses in various international studies for greater clarity on role assignment (7) and appropriate professional guidelines.

The objective of this study is to investigate on a nationwide level attitudes of nurses towards euthanasia and towards their role in euthanasia, and to detect differences in attitudes between groups of nurses based on their socio-demographic and work-related characteristics.

Methods

Study design

In 2007, a postal questionnaire was sent to a random sample of 6000 nurses in Flanders, the northern Dutch speaking region of Belgium where approximately 60% of the population lives. The sample was taken from a federal government database based on statistics from the educational department and the Provincial Commissions. In Belgium, nurses are registered in the province where they work. In the database, 153,586 nurses were registered. We ascertained by means of a small study whether the database could be applied for current study which was positively evaluated. Next, a sample frame of 75,037 nurses was defined by including only those whose place of residence was known (95% of the cases) and who were living in Flanders. Only nurses who were 55 years or less were included to enhance the chances of including working nurses in the sample. Based on their responses on the questionnaire, nurses without any experiences in patient care were also excluded.

The study was performed between August and November 2007. The questionnaire was sent together with a letter of recommendation signed by the two major nursing professional organisations in Flanders. In order to improve the response rate, the survey was conducted by the principles of the Total Design Method (23), including several follow-up mailings. The Ethics Committee of the University Hospital of the Vrije Universiteit Brussel granted ethical approval of the study design and questionnaire.

Questionnaire

The questionnaire consisted of pre-structured questions and was developed in different phases. After studying the literature, a draft questionnaire was developed which was reviewed thoroughly by different experts on the topic (an ethicist, a health scientist, a medical sociologist, and two nurses, all experienced in end-of-life research) and discussed in a focus group (including a palliative home care nurse, a psychologist specialising in palliative care, and two nurses working in policymaking on euthanasia). Cognitive testing (24) was finally conducted with 10 nurses to assess comprehension of the questions and answer categories, and question wording.

The questionnaire consisted of 3.5 pages and required approximately 10–15 min to complete. We asked about the nurses' experiences in patient care, in caring for patients at the end of their lives, and in caring for patients for whom – according to the nurses – one or more medical end-of-life decisions with a possible or certain life-shortening effect (such as decisions to withhold or withdraw potentially life-sustaining treatments, decisions to intensify the alleviation of pain/symptoms which may have a life-shortening side effect and decisions to administer drugs explicitly intended to hasten death) were made. Next, we presented 30 statements about the acceptance of euthanasia and other medical end-of-life decisions with a possible or certain life-shortening effect and about the nurse's role in those decisions. Agreement with each statement

was measured on a 5-point Likert scale. As the focus in this paper is on euthanasia and the nurse's role in euthanasia, the 13 statements dealing explicitly with euthanasia are retained. Explored characteristics of nurses included sex, age, educational level, religion/philosophy of life and importance of religion/philosophy of life in professional attitude toward medical end-of-life decisions, years of experiences as a nurse, principal work setting in the last 12 months, work task in the last 12 months, and whether or not they had received any training in palliative care.

Data analysis

For nurses' characteristics and the attitude statements, percentages were presented and multinomial 95% confidence intervals (exact method) calculated. Logistic regression models were fitted for each statement to determine the relation between socio-demographic and work-related characteristics and nurses' attitudes. The dependent variables (the 5-point Likert type scale of the statements) were collapsed in a binary outcome: 'agree' (combining 'strongly agree' and 'agree') against the other categories ('neutral', 'disagree', and 'strongly disagree'). For each regression, interactions were explored. The analyses were performed using StatXact6 (Cytel Studio, Cambridge, MA) and SPSS16.0 (SPSS Inc., Chicago, IL).

Results

Of the 6000 questionnaires sent, 23 were returned because the respondent could not be reached and 3733 responded to the questionnaire (response rate, 62.5%). Age and sex in this group were compared with the selected sample frame (N = 75,037) and were similar with respect to age, but differed in the distribution of sex with a smaller proportion of male respondents in the response group (12% vs. 14% in the sample frame) (data not shown). Of the group that responded to the questionnaire, 412 were excluded: 191 had never finished their nursing education, 2 were living outside of Flanders, 5 were French-speaking, 208 reported never having worked in patient care, and 6 did not give an answer to half or more of the attitude statements. A total study sample remained of 3321 nurses of whom 88% was female, 77% older than 36 years, and 63% Catholic (**Table 1**). Fifty-two percent worked in a hospital. Ninety percent had once cared for a patient at his/her end-of-life.

Table 1 - Characteristics of the study population (N=3321)*

Socio-demographics	no.	%	[95% CI]†
Sex			
Men	410	12.4	[11.1-13.7]
Women	2909	87.6	[86.3-88.9]
Age			
22-35	756	22.9	[21.1-24.6]
36-45	1371	41.5	[39.4-43.5]
46-55	1180	35.7	[33.7-37.7]
Educational level			
Diploma/Associate degree	1504	45.5	[43.4-47.5]
Baccalaureate degree	1691	51.1	[49.0-53.2]
Master's degree	114	3.4	[2.8-4.3]
Religious affiliation/philosophy of life			
Catholic	2051	62.5	[60.3-64.8]
Protestant	16	0.5	[0.2-0.9]
Other religion	46	1.4	[0.9-2.0]
Religious, but not a particular church	682	20.8	[19.0-22.7]
Non-religious (specific philosophy)	132	4.0	[3.2-5.0]
Non-religious (no specific philosophy)	352	10.7	[9.4-12.2]
Self-reported importance of religion/ philosophy of life in their professional attitudes towards medical end-of-life decisions			
(totally) not important	1252	38.1	[36.1-40.1]
Neutral	957	29.1	[27.2-31.0]
(very) important	1079	32.8	[30.9-34.8]
Work related characteristics and experiences			
Experience as a nurse, y			
Mean ± SD		16.1 ± 8.6	
Median [interquartile range]		16 [9-23]	
Work status in last 12 months			
Full-time	1394	42.1	[40.1-44.2]
Part-time	1570	47.4	[45.3-49.5]
Unemployed	347	10.5	[9.2-11.8]

Table 1 - Characteristics of the study population (N=3321)* "cont."

Work task in last 12 months			
Nurse	2457	74.2	[72.1-76.2]
Head nurse	220	6.6	[5.6-7.9]
Supervisor of practical training / instructor	89	2.7	[2.0-3.5]
Management	113	3.4	[2.6-4.3]
Other	45	1.4	[0.9-2.0]
None‡	388	11.7	[10.3-13.2]
Principal work setting in last 12 months			
Hospital	1716	51.8	[49.6-54.1]
Nursing home	595	18.0	[16.3-19.7]
Home care	448	13.5	[12.0-15.1]
Other	196	5.9	[4.9-7.0]
None‡	356	10.8	[9.4-12.2]
Training in palliative care			
Yes	836	25.3	[23.7-27.1]
No	2463	74.7	[72.9-76.3]
Ever cared for a patient at his/her end of life			
Yes	2988	90.4	[89.2-91.5]
No	317	9.6	[8.5-10.8]
Cared for a patient at his/her end of life in last 12 months			
No	1451	44.7	[42.6-46.8]
Yes, for less than 5 patients	977	30.1	[28.2-32.1]
Yes, for 5 or more patients	817	25.2	[23.4-27.0]
Experiences with medical end-of-life decisions in last 12 months			
No	1608	49.6	[47.5-51.7]
Yes, with less than 3 patients	786	24.3	[22.5-26.1]
Yes, with 3 or more patients	847	26.1	[24.3-28.0]

* Data are presented as numbers and percentages unless otherwise specified. Percentages may not add to 100 due to rounding. Missing data for socio-demographics range from 2 (sex) to 42 (religion), for work related characteristics and experiences from 9 (work task) to 80 (experiences with medical end-of-life decisions in last 12 months).
† Multinomial 95% Confidence Intervals, exact method.
‡ 'Respondent is unemployed' or 'the function/work setting is not related to nursing'.

Attitudes towards euthanasia

Ninety-two percent of nurses accepted euthanasia for patients with a terminal illness with extreme uncontrollable pain or other distress (**Table 2**). Fifty-seven percent were supportive of life-ending without the patient's request when the patient is suffering unbearably and not capable of making decisions. Seventy percent of nurses thought that sufficient availability of good palliative care prevents almost all requests for euthanasia. Putting the patient into a coma until death was for 26% a better alternative to euthanasia. However, 44% of nurses disagreed with that statement.

Table 2 - Attitudes of nurses towards euthanasia and towards their role in euthanasia (N=3321)*

Statements on euthanasia	% [95% CI]† Disagree or strongly disagree	Neutral	Agree or strongly agree
1. The use of drugs in lethal doses on the explicit request of the patient is acceptable for patients with a terminal illness with extreme uncontrollable pain or other distress	3.7[2.9-4.5]	4.6[3.8-5.6]	91.7[90.5-92.8]
2. If a terminally ill patient is suffering unbearably and is not capable of making decisions, the physician should be allowed to administer drugs in lethal doses	20.9[19.2-22.6]	22.5[20.8-24.3]	56.6[54.5-58.6]
3. Sufficient availability of high-quality palliative care prevents almost all requests for euthanasia	10.2[9.0-11.5]	20.3[18.6-22.0]	69.5[67.6-71.4]
4. Putting the patient into a coma until death is a better alternative than euthanasia	43.5[41.4-45.5]	30.8[28.8-32.7]	25.8[24.0-27.7]
5. Permitting the use of drugs in lethal doses on the explicit request of the patient will gradually lead to an increase in the use of drugs in lethal doses without a request of the patient	48.5[46.4-50.6]	34.3[32.3-36.3]	17.3[15.7-18.9]
6. Permitting the use of drugs in lethal doses on the explicit request of the patient will harm the relationship between patients and physicians	78.2[76.4-79.9]	13.2[11.8-14.6]	8.7[7.5-9.9]
Statements on nurses' role in euthanasia			
1. The patient will address his or her request for euthanasia more often to a nurse than to a physician	7.7[6.6-8.9]	31.7[29.8-33.7]	60.6[58.6-62.7]
2. The physician has to discuss the patient's request for euthanasia with the nurses who have regular contact with the patient	2.3[1.8-3.0]	7.8[6.7-8.9]	89.9[88.6-91.1]
3. Whenever it is decided to administer drugs in lethal doses, it has to be discussed with the involved nurses	4.3[3.5-5.2]	7.1[6.1-8.2]	88.6[87.2-89.9]
4. In no case, I would be prepared to administer drugs in lethal doses with the explicit intention of ending the patient's life	42.7[40.6-44.8]	24.8[23.1-26.7]	32.5[30.5-34.4]
5. Administering drugs in case of euthanasia could be a task that nurses are allowed to perform	61.3[59.3-63.3]	22.5[20.8-24.3]	16.2[14.7-17.8]
6. Most nurses are acquainted with which actions they are allowed to perform in case of euthanasia	35.9[33.9-37.9]	30.3[28.4-32.2]	33.8[31.8-35.8]
7. In case of euthanasia, the nurse's task is restricted to the care of the patient and his or her next of kin	26.8[25.0-28.7]	20.3[18.7-22.0]	52.9[50.1-55.0]

* Percentages may not add to 100 due to rounding. Missing data for statements on euthanasia range from 7 (statement 1) to 29 (statement 5) and for nurses' role in euthanasia from 9 (statement 5) to 21 (statement 6).

† Multinomial 95% Confidence Intervals, exact method.

Attitudes towards nurses' role in euthanasia
Sixty-one percent of nurses agreed that a patient would be more likely to address his/her euthanasia request to a nurse rather than to a physician (**Table 2**). Eighty-nine percent of nurses agreed with nurses' involvement in euthanasia discussion. Concerning the administering of lethal drugs, more variation was reported. A third of nurses (33%) would in no case be prepared to administer lethal drugs; however, 43% would. Sixty-one percent of nurses disagreed with the statement that administering drugs in case of euthanasia could be a task that nurses are allowed to perform. Fifty-three percent agreed that the task of the nurse is restricted to patient and family care.

Characteristics related with nurses' attitudes towards euthanasia
Religious nurses – of any denomination – and nurses who rated their religion as important in their professional attitudes towards euthanasia and other end-of-life decisions were more opposed to euthanasia than nonreligious nurses and those nurses who rated their religion as not important (**Table 3**). Catholic nurses also agreed more often than non-religious nurses with the avoidance of euthanasia requests by good palliative care. Older nurses were more likely than younger nurses to support life-ending without the patient's request. They also believed more in euthanasia prevention by palliative care, and in sedation as an alternative to euthanasia. Bedside nurses gave more support to euthanasia than nurses working in a different function. Head nurses and nurses working in a management function gave less support to life-ending without the patient's request. Nurses who had cared in the last year for 3 or more patients for whom a medical end-of-life decision has been made agreed more often with sedation as an alternative to euthanasia than those who did not.

Table 3 - Characteristics of nurses supporting statements on euthanasia*

	Statement 1 Acceptance of euthanasia		Statement 2 Acceptance of life ending without patient's request		Statement 3 Prevention by palliative care		Statement 4 Sedation as alternative		Statement 5 'Slippery slope' argument		Statement 6 Harm relationship with patients	
	OR	95% CI	OR	95% CI	OR	95% CI	OR	95% CI	OR	95% CI	OR	95% CI
Age‡												
22-35	†	†	1.00	1.00, 1.00	1.00	1.00, 1.00	1.00	1.00, 1.00	†	†	1.00	1.00, 1.00
36-45	†	†	1.36	1.14, 1.64	1.10	0.90, 1.33	1.34	1.07, 1.67	†	†	1.57	1.09, 2.27
46-55	†	†	1.50	1.24, 1.81	1.60	1.30, 1.97	1.82	1.45, 2.28	†	†	1.73	1.20, 2.51
Education												
Diploma/Associate degree	†	†	†	†	†	†	1.00	1.00, 1.00	1.00	1.00, 1.00	†	†
Baccalaureate degree	†	†	†	†	†	†	0.82	0.70, 0.97	0.71	0.58, 0.86	†	†
Master's degree	†	†	†	†	†	†	0.72	0.45, 1.17	0.76	0.45, 1.28	†	†
Religious affiliation/philosophy of life												
Non-religious (no specific philosophy)	1.00	1.00, 1.00	†	†	1.00	1.00, 1.00	†	†	1.00	1.00, 1.00	†	†
Non-religious (specific philosophy)	0.39	0.12, 1.30	†	†	0.68	0.45, 1.03	†	†	1.54	0.84, 2.82	†	†
Catholic	0.18	0.07, 0.45	†	†	1.78	1.40, 2.28	†	†	1.91	1.30, 2.80	†	†
Protestant	0.03	0.01, 0.12	†	†	3.50	0.77, 15.79	†	†	4.42	1.48, 13.17	†	†
Other religion	0.04	0.01, 0.11	†	†	1.92	0.91, 4.09	†	†	1.75	0.76, 4.03	†	†
Religious, but not a particular church	0.29	0.11, 0.73	†	†	1.17	0.89, 1.54	†	†	1.54	0.84, 2.82	†	†
Religion/philosophy of life importance§												
Important (vs.neutral/not important)	0.40	0.31, 0.52	0.68	0.59, 0.79	1.59	1.33, 1.90	1.29	1.09, 1.52	1.76	1.45, 2.13	†	†
Work task during last 12 months												
Bedside nurse (vs. other)	1.40	1.06, 1.86	†	†	†	†	†	†	†	†	†	†
Head nurse (vs. other)	†	†	0.67	0.51, 0.89	1.41	1.01, 1.96	†	†	†	†	†	†
Management (vs. other)	†	†	0.50	0.34, 0.74	†	†	†	†	†	†	†	†

Table 3 - Characteristics of nurses supporting statements on euthanasia* "cont."

Principal work setting in last 12 months												
Nursing home (vs. other)	0.63	0.47, 0.86	†	†	†	†	†	†	†	†	†	†
Home care (vs. other)	†	†	†	†	†	†	†	†	1.34	1.04, 1.74	†	†
Training in palliative care												
Yes (vs. no)	†	†	0.84	0.72, 0.99	1.57	1.30, 1.91	†	†	0.73	0.58, 0.91	†	†
Ever cared for a patient at his/her end of life												
Yes (vs. no)	†	†	†	†	1.78	1.39, 2.29	†	†	†	†	†	†
Experiences with medical end-of-life decisions in last 12 months‖												
No	†	†	†	†	†	†	1.00	1.00, 1.00	†	†	†	†
Yes, but less than 3 patients	†	†	†	†	†	†	1.02	0.83, 1.25	†	†	†	†
Yes, and 3 or more patients	†	†	†	†	†	†	1.58	1.31, 1.92	†	†	†	†

* Separate logistic regression models for each statement were fitted [agreement (1) vs. other (0)]. Agreement means 'agree or strongly agree'. Other means 'disagree or strongly disagree' or 'neutral'. The full description of the statements is presented in table 2. Presented figures are odds ratios and 95% confidence intervals. Independent variables which have no significant relationships are not presented in the table.

† Entered in the regression but not significant and consequently eliminated by the stepwise procedure.

‡ A problem of multi-collinearity between age and years of experiences as a nurse made us omit the latter.

§ Importance of religion or philosophy of life towards professional attitude on medical end-of-life decisions.

‖ Multi-collinearity occurred between experiences with caring for patients at the end of their lives and experiences with medical end-of-life decisions in the last 12 months. The first variable has been omitted, as a positive answer on the second question automatically imply a positive answer on the first.

Characteristics related with nurses' attitudes towards their role in euthanasia

Religious nurses – especially Catholic nurses – and those who rated their religion as important agreed less often than non-religious nurses and those who rated their religion as not important with administering drugs being a possible nursing task, were more often not prepared to administer lethal drugs, and believed more often in the care restriction (**Table 4**). The associations found with religious nurses were also found with female nurses in comparison to male nurses. Nurses with a bachelor or master's degree were less supportive of the care restriction, and more prepared to administer lethal drugs than nurses with a basic diploma in nursing. Nurses who work at the bedside agreed less often that a patient's request has to be discussed with nurses and more often with the care restriction than nurses working in other functions. Further, home care nurses were less prepared to administer lethal drugs than nurses working in other settings. Home care and nursing home nurses gave less support to the administering of lethal drugs being a possible nursing task than nurses working in other settings.

Table 4 - Characteristics of nurses supporting statements on nurses' role in euthanasia*

	Statement 1 Euthanasia request rather to nurse than physician		Statement 2 Discussion of the patient's request		Statement 3 Discussion with nurses required in case of administer lethal drugs		Statement 4 Never prepared to administer lethal drugs		Statement 5 Administer lethal drugs: possible nurse task		Statement 6 Acquainted with actions allowed in case of euthanasia		Statement 7 Nurse task in euthanasia restricted to care for patient/relatives	
	OR	95% CI	OR	95% CI	OR	95% CI	OR	95% CI	OR	95% CI	OR	95% CI	OR	95% CI
Sex														
Women (vs. men)	†	†	†	†	†	†	1.74	1.33, 2.29	0.31	0.24, 0.39	†	†	1.87	1.49, 2.35
Age‡														
22-35	†	†	1.00	1.00, 1.00	†	†	†	†	†	†	1.00	1.00, 1.00	1.00	1.00, 1.00
36-45	†	†	1.11	0.84, 1.46	†	†	†	†	†	†	1.32	1.08, 1.61	1.32	1.10, 1.59
46-55	†	†	1.74	1.27, 2.38	†	†	†	†	†	†	1.50	1.22, 1.84	1.30	1.07, 1.58
Education														
Diploma/Associate degree	1.00	1.00, 1.00	†	†	1.00	1.00, 1.00	1.00	1.00, 1.00	†	†	1.00	1.00, 1.00	1.00	1.00, 1.00
Baccalaureate degree	0.78	0.68, 0.91	†	†	1.43	1.14, 1.78	0.70	0.60, 0.83	†	†	0.66	0.57, 0.77	0.63	0.55, 0.74
Master's degree	0.74	0.49, 1.12	†	†	2.14	0.98, 4.68	0.54	0.34, 0.87	†	†	0.62	0.40, 0.96	0.49	0.33, 0.75
Religious affiliation/philosophy of life														
Non-religious (no specific philosophy)	†	†	†	†	†	†	1.00	1.00, 1.00	1.00	1.00, 1.00	†	†	1.00	1.00, 1.00
Non-religious (specific philosophy)	†	†	†	†	†	†	1.27	0.77, 2.07	1.54	0.97, 2.44	†	†	0.85	0.56, 1.30
Catholic	†	†	†	†	†	†	1.92	1.42, 2.59	0.64	0.48, 0.86	†	†	1.40	1.10, 1.78
Protestant	†	†	†	†	†	†	6.40	2.17, 18.87	0.20	0.03, 1.58	†	†	2.27	0.79, 6.57
Other religion	†	†	†	†	†	†	3.86	1.97, 7.56	0.68	0.27, 1.69	†	†	1.59	0.83, 3.04
Religious, but not a particular church	†	†	†	†	†	†	1.26	0.77, 2.07	0.90	0.65, 1.25	†	†	1.13	0.86, 1.49
Religion/philosophy of life importance§														
Important (vs. neutral /not important)	1.21	1.04, 1.41	†	†	†	†	1.69	1.44, 1.99	0.80	0.64, 0.99	†	†	1.32	1.13, 1.54

Table 4 - Characteristics of nurses supporting statements on nurses' role in euthanasia* "cont."

Work task during last 12 months														
Bedside nurse (vs. other)	†	†	0.67	0.50, 0.91	†	†	†	†	†	†	†	†	1.42	1.20, 1.68
Head nurse (vs. other)	†	†	†	†	2.19	1.18, 4.08	†	†	†	†	†	†	†	†
Management (vs. other)	0.43	0.28, 0.65	†	†	†	†	†	†	†	†	†	†	†	†
Principal work setting in last 12 months														
Nursing home (vs. other)	†	†	†	†	†	†	†	†	0.58	0.44, 0.77	†	†	†	†
Home care (vs. other)	0.64	0.51, 0.79	0.65	0.49, 0.88	0.52	0.40, 0.68	1.44	1.15, 1.80	0.50	0.36, 0.70	†	†	†	†
Experiences with medical end-of-life decisions in last 12 months‖														
No	1.00	1.00, 1.00	†	†	†	†	1.00	1.00, 1.00	†	†	1.00	1.00, 1.00	†	†
Yes, but less than 3 patients	1.28	1.06, 1.54	†	†	†	†	0.85	0.70, 1.03	†	†	1.48	1.23, 1.78	†	†
Yes, and 3 or more patients	1.28	1.08, 1.53	†	†	†	†	0.73	0.60, 0.88	†	†	1.72	1.44, 2.05	†	†

* Separate logistic regression models for each statement were fitted [agreement (1) vs. other (0)]. Agreement means 'agree or strongly agree'. Other means 'disagree or strongly disagree' or 'neutral'. The full description of the statements is presented in table 2. Presented figures are odds ratios and 95% confidence intervals. Independent variables which have no significant relationships are not presented in the table.

† Entered in the regression but not significant and consequently eliminated by the stepwise procedure.

‡ A problem of multi-collinearity between age and years of experiences as a nurse made us omit the latter.

§ Importance of religion or philosophy of life towards professional attitude on medical end-of-life decisions.

‖ Multi-collinearity occurred between experiences with caring for patients at the end of their lives and experiences with medical end-of-life decisions in the last 12 months. The first variable has been omitted, as a positive answer on the second question automatically imply a positive answer on the first.

Discussion

Nurses have a high acceptance rate of euthanasia for patients with a terminal illness with extreme uncontrollable pain or other distress and are convinced that physicians should discuss euthanasia decisions with them; however, the question of their role in performing euthanasia elicits dissent.

We used for this study an extensive nationwide nurse registration database which was positively tested on applicability for present study. We took a large sample of nurses and included only those with patient care experiences. The questionnaire was succinct and comprehensively tested. The study was endorsed by authoritative professional nursing groups. The response rate is considered as good as compared to other surveys among health care professionals (25). These factors all strengthen the validity and reliability of our results. However, at the time of the study not all provincial commissions had fully updated their database. As a consequence, there might be an underrepresentation of younger nurses. As younger nurses tend to agree less often on some statements than older nurses, prudence is warranted when interpreting some results. Furthermore, somewhat fewer men had cooperated in the study in comparison with the database. However, there were no differences in euthanasia acceptance based on sex, only for three statements concerning their role in euthanasia performance.

Flemish nurses (92%) strongly agree with the option of euthanasia for terminally ill patients. The same question has been asked to physicians in Flanders and although a large proportion was also supportive of euthanasia (78%), the percentage was significantly lower (26). Five years of legislation in Belgium may have contributed to this higher acceptance among nurses as found in our study compared with the physician study performed before the euthanasia law in our country. However, this higher acceptance among nurses is in line with several studies in other countries, also in countries without a permissive legal framework towards euthanasia (16;27;28). Furthermore, a legal climate of a country can have an influence on attitudes, but it is known that it occurs in a lesser degree than its influence it has on practices (26;29). Therefore another more plausible explanation of nurses' higher acceptance may be their more personal and direct confrontation with the pain and suffering of their patients. The alleviation of pain and suffering is the nurse's primal concern (30), and when this cannot be alleviated, nurses may believe that life-ending is a justifiable option (31). This view is confirmed by bedside nurses being, according to our study, more supportive of euthanasia and by our finding that 70% of nurses believe that optimal palliative care prevents euthanasia requests. This belief in the preventive force of palliative care perhaps reflects their conviction that pain and physical suffering are the main reasons why patients wish to die (32). This prevention of unnecessary pain and suffering might also be the justification for the acceptance (57%) that physicians should be allowed to end the life of terminally ill patients who suffer unbearably and are not capable of making decisions. Among the nurses who reject life-ending without request are many head nurses and nurses working in

management functions. Their distance from the direct confrontation with the patient's suffering may explain this rejection. However, further studies are needed to explore the motivations of nurses in their conception and differentiation of possible life-ending acts.

In some studies, it is claimed that the use of drugs to put the patient into a coma until death is considered as an alternative to euthanasia (31;33;34). Especially palliative care nurses adhere to that vision (31). Our study shows that 26% of nurses agree with this practice being a better alternative to euthanasia. Among those who are proponents are more nurses with a lot of experiences with end-of-life decisions. Some health care institutions in Flanders do favour a policy of supplanting euthanasia by putting the patient into a coma until death and in the Netherlands, it has been suggested that this practice is already going on (4). We have to consider that nurses are the executors of putting the patient into a coma until death and that they experience the direct consequences and difficulties of this practice (35;36).

As in earlier studies (30), we found that the acceptance of euthanasia is higher than the willingness to be personally involved in it. However, nurses clearly want to be involved in euthanasia decision-making. In practice this wish is not always granted as physicians not always consult nurses in making their decision (3;12;13;37). A legal obligation for physicians to consult nurses in euthanasia and the univocal wish of nurses to take part in decision-making seems to be not determined enough for physicians to involve nurses. As for euthanasia performance, 61% of nurses do not think that this should be done by them. However, a quite high percentage (43%) would be prepared to administer lethal drugs, although nurses are – according to current Belgian euthanasia law – not allowed to do so (38). An explicit statement in legal documents – in this case in a euthanasia law – seems not to restrain nurses to administer lethal drugs. In previous studies (8;9;12;13) it was already found that nurses administer lethal drugs although euthanasia was prohibited and although nurses would therefore find themselves in a precarious legal position. The study does not provide information which would allow conclusions to be drawn as to the circumstances in which they would actually be prepared to do so. It is probable that they would be willing to administer lethal drugs if a physician requested them to, which confirms with our findings that home care nurses are less prepared to administer lethal drugs. Delegation of such acts from physicians to nurses is less common in home care than in institutionalised care (12;13). Compared to hospital nurses, home care and nursing home nurses also consider administering lethal drugs less often a task nurses are allowed to perform. Female nurses (the vast majority) are less inclined than male nurses to administer lethal drugs, and to consider it as a task that nurses are allowed to perform. They also believe more often that the task of nurses in euthanasia is restricted to patient and family care. This reluctance by female nurses could be a result of a more care-orientated vision in females. It can be questioned whether or not gender-stereotypes (e.g. females are more care-orientated and males more act-orientated) also prevail in nursing. As masculinisation of this profession

is currently increasing, much more attention should be given to the consequences for nursing practice concerning end-of-life care.

We also found that older nurses believe more in palliative care preventing euthanasia requests, in putting the patient into a coma until death as an alternative to euthanasia, and agree more often with life-ending without request. Those aspects actually concern the intensification of pain and/or symptom alleviation which was possibly in former years more common practice and – more importantly – perceived by nurses as a more common practice. We may wonder if the age difference is due to greater experience among the older nurses or to a cohort effect, i.e. a difference between younger and older generations (15), for example due to a different societal context and/or other emphases in nursing education in former years. Another finding of our study which also confirms previous studies is that the more a nurse is religiously inspired and more particularly a Catholic, the more s/he opposes euthanasia (15;17;31;39). However, we have to make nuances, as most nurses support euthanasia, even a majority of the nurses who are religiously inspired, including Catholics. Despite their church's strong moral stance against euthanasia, Catholic nurses believe that euthanasia should be an option, albeit as a last resort, as demonstrated by their belief in the efficacy of palliative care in preventing euthanasia requests.

Finally, it has to be noted that although most nurses agree with the practice of euthanasia, there is a small proportion of nurses (4%) disagreeing with this practice. We can wonder whether those nurses can work satisfactory in a system where it does take place. However, the euthanasia law have provided a clause that nobody can be forced to cooperate in the performance of euthanasia (38). Requesting euthanasia should always be a right for terminally ill patients, but should never be an obligation for healthcare professionals to cooperate in it.

We conclude that there is a substantial majority of nurses supporting the practice of euthanasia for patients with a terminal illness with extreme uncontrollable pain or other distress and for their own involvement in consultancy about euthanasia requests. There is, however, uncertainty about their proper role in the performance of euthanasia. There is a mix of reasons for this uncertainty, ranging from religious convictions and sex effects to work hierarchy and possible reticence toward an active technical role for nurses. These findings have implications for policymakers and health care professionals all over the world, as nurses worldwide are confronted with euthanasia. It is important to assign nurses a task in the societal and ethical debate on euthanasia, to recognise their views in the conception of legal regulations, and especially to adequately translate their role in euthanasia in clear guidelines on the work floor, taking into account characteristics of health care settings and personal preferences.

Acknowledgements

We thank the thousands of nurses who provided the study data; Johan Vanoverloop (Vrije Universiteit Brussel) for statistical advice; the helpful comments of Jane Ruthven (English editing) and Koen Meeussen; and the Federal Ministry of Public Health, Safety of the Food Chain and Environment, Department Basic Health Care and Emergency Management for access to their federal government database. This study was supported by a grant from the Fund for Scientific Research Flanders, Belgium (G.0503.05N). The funding organisation had no role in study design, in collection, analysis, and interpretation of data, in the writing of the article, and in the decision to submit the paper for publication.

References

(1) Kuhse H, Singer P, Baume P, Clark M, Rickard M. End-of-life decisions in Australian medical practice. Med J Aust 1997; 166(4):191-196.
(2) Meier DE, Emmons CA, Wallenstein S, Quill T, Morrison RS, Cassel CK. A national survey of physician-assisted suicide and euthanasia in the United States. N Engl J Med 1998; 338(17):1193-1201.
(3) van der Heide A, Deliens L, Faisst K et al. End-of-life decision-making in six European countries: descriptive study. Lancet 2003; 362(9381):345-350.
(4) van der Heide A, Onwuteaka-Philipsen BD, Rurup ML et al. End-of-life practices in the Netherlands under the Euthanasia Act. N Engl J Med 2007; 356(19):1957-1965.
(5) Seale C. National survey of end-of-life decisions made by UK medical practitioners. Palliat Med 2006; 20(1):3-10.
(6) De Beer T, Gastmans C, Dierckx de Casterlé B. Involvement of nurses in euthanasia: a review of the literature. J Med Ethics 2004; 30(5):494-498.
(7) De Bal N, Gastmans C, Dierckx de Casterlé B. Nurses' involvement in the care of patients requesting euthanasia: a review of the literature. Int J Nurs Stud 2008; 45(4):626-644.
(8) Kuhse H, Singer P. Voluntary euthanasia and the nurse: an Australian survey. Int J Nurs Stud 1993; 30(4):311-322.
(9) Asch DA. The role of critical care nurses in euthanasia and assisted suicide. N Engl J Med 1996; 334(21):1374-1379.
(10) Ferrell B, Virani R, Grant M, Coyne P, Uman G. Beyond the Supreme Court decision: nursing perspectives on end-of-life care. Oncol Nurs Forum 2000; 27(3):445-455.
(11) Tanida N, Asai A, Ohnishi M et al. Voluntary active euthanasia and the nurse: a comparison of Japanese and Australian nurses. Nurs Ethics 2002; 9(3):313-322.
(12) Bilsen JJ, Vander Stichele RH, Mortier F, Deliens L. Involvement of nurses in physician-assisted dying. J Adv Nurs 2004; 47(6):583-591.
(13) Inghelbrecht E, Bilsen J, Mortier F, Deliens L. Factors related to the involvement of nurses in medical end-of-life decisions in Belgium: A death certificate study. Int J Nurs Stud 2008; 45(7):1022-1031.
(14) van Bruchem-van de Scheur G, van der Arend AJ, Huijer Abu-Saad H, Spreeuwenberg C, van Wijmen FC, Ter Meulen RH. The role of nurses in euthanasia and physician-assisted suicide in The Netherlands. J Med Ethics 2008; 34(4):254-258.
(15) Kitchener BA. Nurse characteristics and attitudes to active voluntary euthanasia: a survey in the Australian Capital Territory. J Adv Nurs 1998; 28(1):70-76.
(16) Ryynanen OP, Myllykangas M, Viren M, Heino H. Attitudes towards euthanasia among physicians, nurses and the general public in Finland. Public Health 2002; 116(6):322-331.
(17) Verpoort C, Gastmans C, De Bal N, Dierckx de Casterlé B. Nurses' attitudes to euthanasia: a review of the literature. Nurs Ethics 2004; 11(4):349-365.
(18) Deliens L, van der Wal G. The euthanasia law in Belgium and the Netherlands. Lancet 2003; 362(9391):1239-1240.
(19) Bosshard G, Broeckaert B, Clark D, Materstvedt LJ, Gordijn B, Muller-Busch HC. A role for doctors in assisted dying? An analysis of legal regulations and medical professional positions in six European countries. J Med Ethics 2008; 34(1):28-32.
(20) Broeckaert B. Belgium: towards a legal recognition of euthanasia. European Journal of Health Law 2001; 8:95-107.
(21) Gastmans C, Lemiengre J, de Casterle BD. Role of nurses in institutional ethics policies on euthanasia. J Adv Nurs 2006; 54(1):53-61.
(22) Berghs M, Dierckx de Casterlé B, Gastmans C. The complexity of nurses' attitudes toward euthanasia: a review of the literature. J Med Ethics 2005; 31(8):441-446.
(23) Dillmann DA. The design and administration of mail surveys. Annu Rev Sociol 1991; 17:225-249.
(24) Collins D. Pretesting survey instruments: An overview of cognitive methods. Quality of Life Research 2003; 12(3):229-238.
(25) Asch DA, Jedrziewski MK, Christakis NA. Response rates to mail surveys published in medical journals. J Clin Epidemiol 1997; 50(10):1129-1136.
(26) Miccinesi G, Fischer S, Paci E et al. Physicians' attitudes towards end-of-life decisions: a comparison between seven countries. Soc Sci Med 2005; 60(9):1961-1974.

(27) Kitchener BA. Nurses' attitudes to active voluntary euthanasia: a survey in the ACT. Aust N Z J Public Health 1998; 22(2):276-278.
(28) Rurup ML, Onwuteaka-Philipsen BD, Pasman HR, Ribbe MW, van der Wal G. Attitudes of physicians, nurses and relatives towards end-of-life decisions concerning nursing home patients with dementia. Patient Educ Couns 2006; 61(3):372-380.
(29) Willems DL, Daniels ER, van der Wal G, van der Maas PJ, Emanuel EJ. Attitudes and practices concerning the end of life: a comparison between physicians from the United States and from The Netherlands. Arch Intern Med 2000; 160(1):63-68.
(30) Matzo ML, Schwarz JK. In their own words: oncology nurses respond to patient requests for assisted suicide and euthanasia. Appl Nurs Res 2001; 14(2):64-71.
(31) Verpoort C, Gastmans C, Dierckx de Casterlé B. Palliative care nurses' views on euthanasia. J Adv Nurs 2004; 47(6):592-600.
(32) Young MG, Ogden RD. The role of nurses in AIDS care regarding voluntary euthanasia and assisted suicide: a call for further dialogue. J Adv Nurs 2000; 31(3):513-519.
(33) Seymour JE, Janssens R, Broeckaert B. Relieving suffering at the end of life: practitioners' perspectives on palliative sedation from three European countries. Soc Sci Med 2007; 64(8):1679-1691.
(34) Rietjens J, van DJ, Onwuteaka-Philipsen B, Buiting H, van der Maas P, van der Heide A. Continuous deep sedation for patients nearing death in the Netherlands: descriptive study. BMJ 2008; 336(7648):810-813.
(35) Morita T, Miyashita M, Kimura R, Adachi I, Shima Y. Emotional burden of nurses in palliative sedation therapy. Palliat Med 2004; 18(6):550-557.
(36) Rietjens JA, Hauser J, van der Heide A, Emanuel L. Having a difficult time leaving: experiences and attitudes of nurses with palliative sedation. Palliat Med 2007; 21(7):643-649.
(37) Seale C. Characteristics of end-of-life decisions: survey of UK medical practitioners. Palliat Med 2006; 20(7):653-659.
(38) Belgian Ministry of Justice. Wet betreffende de euthanasie (The Belgian Euthanasia Act). Belgian Law Gazette of June 22, 2002. 22-6-2002.
Ref Type: Bill/Resolution
(39) Asch DA, DeKay ML. Euthanasia among US critical care nurses. Practices, attitudes, and social and professional correlates. Med Care 1997; 35(9):890-900.

Chapter 4

Medical end-of-life decisions: experiences and attitudes of Belgian pediatric intensive care nurses

Els Inghelbrecht, Johan Bilsen, Heidi Pereth, José Ramet, Luc Deliens

Published in American Journal of Critical Care 2009; 18(2): 160-8.

Abstract

Objective To investigate Belgian paediatric intensive care nurses' involvement in and attitudes toward medical end-of-life decisions with a possible or certain life-shortening effect.
Methods Questionnaires were distributed to 141 nurses working in 5 of the 7 paediatric intensive care units in Belgium. Nurses were asked to recall the last child in their care whose treatment involved an end-of-life decision and to describe anonymously their involvement in the decision. Attitudes were ascertained by means of statements and a Likert scale.
Results Questionnaires were completed by 89 nurses (63%). During the preceding 2 years, 76 (85%) had cared for at least 1 child for whom a medical end-of-life decision had been made. Nurses were involved in initiating the decision in 17% of cases, participated in decision making in 50%, and played a role in carrying out the decision in 90%. Only 6% of nurses found it always ethically wrong to hasten the death of a child by administering lethal drugs; most nurses (78%) reported they were prepared to cooperate in administering life-ending drugs in some cases. Most (89%) favoured adapting the law, making life termination of children legally possible in certain cases.
Conclusions Belgian paediatric intensive care nurses are often involved in carrying out medical end-of-life decisions, including administration of life-ending drugs, whereas their participation in decision making is more limited. Most think that the current euthanasia law should be extended to minors so that administering life-ending drugs would be possible for terminally ill children in specific circumstances.

Introduction

General medical studies (1-4) have indicated that end-of-life decisions with a possible or certain life-shortening effect are common in medical practice. Examples include decisions to withhold or withdraw potentially life-sustaining treatments, decisions to intensify pain and/or symptom alleviation with a possible life-shortening side effect, and decisions to administer drugs explicitly intended to hasten death. In several European countries, more than one-third of all deaths are preceded by an end-of-life decision (3). Reports of studies on end-of-life decisions in children indicate that the decision to forgo life-sustaining treatment is the most frequently made decision (5-10), that sedatives and analgesics are regularly used (5;11), and that in about 3% of deaths, a child's death is preceded by the use of drugs explicitly intended to hasten death (12). Explicit requests for drugs intended to hasten death (ie, euthanasia) have been allowed in Belgium since 2002, but only for adult patients and under strict precautions (13). In recent years, however, whether euthanasia should be allowed for children (12 years and older) has been under debate.

At present, most end-of-life care for children occurs in acute hospital settings, especially in pediatric intensive care units (PICUs) (9;10;14;15), where nurses make an extensive contribution to the provision of end-of-life care (16;17). Because nurses are intensely involved in the daily care of vulnerable children (18;19), and more intensive interdisciplinary collaboration in PICUs is recommended (20-22), PICU nurses are increasingly likely to be confronted with end-of-life decisions. However, in Belgium, the physician has the decision-making authority and holds responsibility for the ultimate decision and for carrying it out.

Until now, little has been known about the experiences and attitudes of Belgian PICU nurses toward end-of-life decisions (23). Public and ethical debates about end-of-life decisions, scientific research, and legislation have focused predominately on the role of physicians. It is currently not known whether Belgian PICU nurses are often confronted with end-of-life decisions and, more specifically, with the administration of drugs explicitly intended to hasten death. It is also unclear whether PICU nurses initiate, participate in, or have any input into such decisions. In addition, information has not been available about PICU nurses' attitudes toward different end-of-life decisions in children. Belgian PICU nurses work in a context wherein euthanasia has been legalized and possible expansion of the law to children is currently being debated, so it is important to know the views and experiences of these nurses. Also in other countries, health care professionals working in PICUs are likely to be dealing with terminally ill children and to be confronted with end-of-life decisions. In most countries, little overt discussion about some life-ending practices such as euthanasia is occurring; thus, our investigation stimulates the ongoing debate by providing information from the perspective of nurses. The purpose of this study was to investigate (1) how many Belgian PICU nurses are confronted with end-of-life decisions and what types of end-of-life decisions, (2) the nature of nurses' involvement in end-of-life decisions, and (3) how nurses think about end-of-life decisions in children.

Methods

Study design and setting

A retrospective design and a structured questionnaire were used for the study. All PICUs in Belgium were included in the study. Seven units specialize in the care of seriously ill children (24). Three units—1 Dutch speaking and 2 French speaking— are in Brussels; 3 in Flanders, the Dutch-speaking part of Belgium; and 1 in the Walloon region, the French-speaking part of Belgium. One unit is a general ICU but is generally known to have a very high admission rate for children. The age limit in a PICU is 15 years, but exceptions up to the age of 18 are sometimes made (25). A total of 2 units had a capacity of fewer than 6 beds, 3 units had 7 to 12 beds, and 2 units had more than 12 beds. A total of 208 nurses were working in the 7 PICUs.

Procedure

Recruitment occurred in several phases. First, the head nurse of each PICU was asked for information about the unit (number of beds and total number of nurses working). Second, permission was requested from the board of the nursing department of the involved hospital and the medical head of the unit for the nurses in the unit to participate in the study. A total of 5 (3 Dutch speaking and 2 French speaking) of the 7 units were willing to distribute the questionnaires among their nursing personnel, making a total of 141 nurses included in the study.

Finally, in the spring of 2005, the head nurses of the participating units were asked to fill out a form providing information on the sex, age, years of experience in the unit, and educational level of the nurses on the PICU team. Each head nurse was also responsible for giving each of the nurses working in the unit a questionnaire with a blank envelope. In a cover letter, the nurses were asked to fill in the questionnaire privately and deposit the questionnaire in the sealed envelope in a central box. The envelopes were picked up on an agreed-upon date, and only when all envelopes had been gathered were the questionnaires removed, so that it was impossible to link responses with specific units. No personal information was provided in the questionnaire that could link the responses to specific persons or units. Socio-demographic data on the nurses were requested only in aggregated categories.

The ethics committee of the University Hospital of the Vrije Universiteit Brussel granted ethical approval of the study design and questionnaire. Two of the participating units asked for and were granted additional approval of the ethics committee of their own hospital. All nurses were guaranteed in a cover letter that all information would remain anonymous. Return of the completed questionnaire was considered as consent to participate.

Questionnaire

The questionnaire was developed after a review of instruments used in earlier surveys about end-of-life decisions that have been used internationally and proven

to be valid and reliable (3;26;27). Content validity was established through expert review by a paediatrician working in a PICU, a nurse/health scientist, and a sociologist with experience in development of questionnaires on end-of-life care issues and through testing by 3 paediatric intensive care nurses; some minor adaptations were made to enhance clarity. Attention was paid to the interpretation of the different end-of-life decisions. A forward-backward translation procedure was used to translate the questionnaire from Dutch to French, so that it could be used for PICUs in the French-speaking part of the country and Brussels.

Table 1 - Categorization of ELDs and questions of part one of the questionnaire asking about the experiences and involvement of nurses in ELDs

The different ELDs were categorized as: (a) Non-treatment decision: withholding or withdrawing a probably life-prolonging medical treatment, e.g. being actively removed from inotropes and/or mechanical ventilation; (b) Alleviation of pain/symptom: intensification of pain and/or symptom alleviation with a possible life-shortening side-effect, e.g. use of analgesics and sedativa; (c) Use of life-ending drugs: the administering of drugs with the explicit intention of hastening the patient's death, e.g. use of neuromuscular relaxants and barbiturates.
Nurses were asked: - whether or not they had been confronted with ELDs at their unit in the previous two years; - whether or not they had cared for at least one child for whom an ELD had been made during that period; - to recall the last child in their care whose treatment involved an ELD and to report about: 1) the types of ELDs made for this child and, if more than one type had been made, which ELD they considered to be the most important with regard to life-shortening effect. 2) their possible involvement in this ELD by answering the following questions: - who initiated the discussion about the ELD? - who was involved in the decision-making of the ELD? - did you want to be involved in the decision-making? - were you satisfied with your involvement in the decision-making? - What role did you have in the carrying out of the ELD? Examples of that part: were you involved in the practical preparations? Were you present at the carrying out in order to assist the physician?

The questionnaire contained structured questions about experiences with and attitudes toward end-of-life decisions. First, nurses were asked about their experiences with and their involvement in end-of-life decisions, recalling the last child in their care whose treatment involved an end-of-life decision (**Table 1**). Second, 5-point Likert-type choices were made about 15 statements about end-of-life decisions in children. Finally, the respondents provided demographic data.

Data analyses

Before the analyses, the response sample was tested for representativeness of the total sample of nurses in the 5 participating units with respect to sex, age, years of experience, and educational level. Descriptive results were presented in frequency tables, and differences in distribution were calculated by using the Fisher exact test. SPSS 15.0 (SPSS Inc, Chicago, Illinois) and StatXact 6 (Cytel Corp, Cambridge, Massachusetts) were used for the statistical computations, and a probability level of .05 was set to determine statistical significance of associations.

Results

Characteristics of nurses

Of the 141 nurses in the 5 participating PICUs, 89 completed and returned the questionnaire (63% response rate). Of the responding nurses, most were female (84%) and spoke Dutch (70%). More than half were less than 35 years old (58%), had worked in the PICU for 10 years or less (62%), and had a religious affiliation or considered themselves religious (61%). Sex, age, years of practice in the PICU, and educational level were compared with the total sample of nurses working in the 5 units. The nurses who responded did not differ significantly from the total sample on any characteristic (**Table 2**).

Table 2 - Characteristics of nurses: respondents versus total sample

		no. (%)				
		Respondents ***n = 89***		**Total sample** ***n = 141***		*p* value*
Sex†	Male	14	(15.9)	16	(11.4)	0.32
	Female	74	(84.1)	12 5	(88.6)	
Age	< 35 years	52	(58.4)	70	(49.6)	0.44
	35 – 45 years	22	(24.7)	41	(29.1)	
	> 45 years	15	(16.8)	30	(21.3)	
Years in practice	< 5 year	34	(38.2)	50	(35.5)	0.43
	5 – 10 years	21	(23.6)	35	(24.8)	
	10 – 20 years	20	(22.5)	23	(16.3)	
	> 20 years	14	(15.7)	33	(23.4)	
Educational level	Master's degree‡	3	(3.4)		-	0.71
	Baccalaureate degree	84	(94.4)	135	(95.7)	
	Associate degree/Diploma	2	(2.2)	6	(4.3)	
Religious affiliation	Christian	24	(27.0)		n.a.§	
	Catholic	14	(15.7)			
	Other religion	3	(3.3)			
	Religious, but no specific religion	13	(14.6)			
	Humanist	16	(18.0)			
	Not religious	19	(21.3)			
Importance of religion in ELDs‖	Important	25	(28.1)		n.a.§	
	Neutral	35	(39.3)			
	Unimportant	29	(32.6)			
Language	Dutch	62	(69.7)		n.a.§	
	French	27	(30.3)			

* Comparison of respondent group and the total sample were tested by Fisher's Exact test.
† One case was missing in the response group.
‡ Nurses with a university degree were not included in the significance testing.
§ n.a.= not available
‖ Importance of religion for professional attitude towards end-of-life decisions with a possible or certain life-shortening effect.

Medical end-of-life decisions in PICUs

Of the 89 nurses who completed the questionnaire, 85 (96%) indicated that at least 1 end-of-life decision had occurred in the PICU in the preceding 2 years. A

total of 76 nurses (85%) had also cared for a child for whom at least 1 end-of-life decision was made during that period (data not shown). Age and sex of the children that the nurses remembered are presented in **Table 3**.

Table 3 - Characteristics of children with an ELD (N=70)

		no. (%) of children
Sex*	Male	25 (37.3)
	Female	42 (62.7)
Age†	< 1 month	4 (6.1)
	1 – 12 months	18 (27.3)
	1 – 5 years	28 (42.4)
	6 – 11 years	6 (9.1)
	> 12 years	10 (15.2)

* Three cases were missing.
† Four cases were missing.

Regarding the last child with an end-of-life decision that the nurses had cared for, nurses reported a non-treatment decision in 88%, intensification of pain and/or symptom alleviation with a possible life-shortening side effect in 72%, and the administration of drugs explicitly intended to hasten death in 34% (**Table 4**). A combination of 2 end-of-life decisions had been made in nearly half of the cases (47%), and a combination of 3 end-of-life decisions occurred in 23% of the cases. Further, nurses were asked what type of end-of-life decision they considered the most important made. In nearly half of the end-of-life decisions (49%), a non-treatment decision was the most important decision made. The administering of drugs explicitly intended to hasten death was rated as the most important decision in 19% of the cases.

Nurses' involvement in end-of-life decisions

A total of 70 nurses provided information on their involvement in the end-of-life decision that they considered the most important with respect to the life-shortening effect on the child (**Table 5**). In most cases (83%), a nurse did not initiate discussion of the end-of-life decision. A nurse was involved in the decision making in half of all cases. This involvement was mostly together with the patient's physician and the patient's family and in some cases, just with the physician. When asked about their own involvement in the carrying out of end-of-life decisions, 9 of 10 nurses reported having had some kind of role. They were mostly present during the implementation to support the patient and/or the patient's family (76%), or they had a role in the practical preparation (65%). Nurses sometimes carried out the end-of-life decision themselves, more likely with the presence of the physician (46%) than without (15%). Here, we found a difference between the 3 end-of-life decisions. Nurses were more likely to be present to assist the physician in the case of a non-treatment decision than in the case of the other 2 end-of-life decisions (P = .03). On the other hand, nurses were more likely to carry the decision out without the presence of the physician in cases of the use of life-ending drugs and alleviation of pain/ symptoms than they were when a non-treatment decision was made (P = .01). Finally, nurses

administered the drugs explicitly intended to hasten death with the attendance of the physician in 62% of cases and without the attendance of the physician in 31%.

Table 4 - Medical end-of-life decisions (ELDs) reported by nurses (N = 76)*

	no. (%)
Total ELDs made for all children	
Non-treatment decision†	65 (87.6)
Alleviation of pain/symptom†	53 (71.6)
Use of life-ending drugs‡	25 (34.2)
Types of ELDs made per child‡	
Non-treatment decision	14 (19.2)
Alleviation of pain/symptom	5 (6.8)
Use of life-ending drugs	3 (4.1)
Non-treatment decision + Alleviation of pain/symptom	29 (39.7)
Non-treatment decision + Use of life-ending drugs	4 (5.5)
Alleviation of pain/symptom + Use of life-ending drugs	1 (1.4)
Non-treatment decision + Alleviation of pain/symptom + Use of life-ending drugs	17 (23.3)
Most important ELD made per child §	
Non-treatment decision	34 (48.6)
Alleviation of pain/symptom	23 (32.9)
Use of life-ending drugs	13 (18.6)

* Based on the last child in their care whose treatment involved an end-of-life decision with a possible or certain life-shortening effect.
† Two cases were missing.
‡ Three cases were missing.
§ Most important end-of-life decision made regarding the life-shortening effect as assessed by the nurse. Six cases were missing.

When asked about their own involvement in decision making, 24 of the 70 nurses (34%) reported that they were themselves involved in the decision making. All nurses were asked if they wished to be involved; 48 of the 68 nurses who answered the question (71%) indicated that they did (data not shown). Of those nurses, 26 (54%) were not involved in the decision making. When nurses did not wish to be involved, most (90%) were effectively not involved. A total of 48 of 68 responding nurses (71%) were satisfied with their involvement in decision making. Of the 24 nurses who were involved in decision making, 21 nurses (88%) were satisfied with their involvement. Of the 44 nurses who were not involved, 27 (61%) were also satisfied with their non-involvement.

Table 5 - Nurses' involvement in the most important end-of-life decision (ELD) made (N = 70)

	no. (%)							
Involvement in the	**ELD** *n = 70*		**Non-treatment decision** *n = 34*		**Alleviation of pain/symptom** *n = 23*		**Use of life-ending drugs** *n = 13*	
initiation of the discussion about the end-of-life decision:*								
No nurse	58	(82.9)	28	(82.4)	19	(82.6)	11	(84.6)
Nurse alone	3	(4.3)	3	(8.8)	-		-	
Nurse with physician	7	(10.0)	3	(8.8)	3	(13.0)	1	(7.7)
Nurse with physician and family	2	(2.9)	-		1	(4.3)	1	(7.7)
end-of-life decision-making:*								
No nurse	35	(50.0)	18	(52.9)	9	(39.1)	8	(61.5)
Nurse with physician	8	(11.4)	3	(8.8)	3	(13.0)	2	(15.4)
Nurse with physician and family	22	(31.4)	11	(32.4)	9	(39.1)	2	(15.4)
Nurse with physician, family and child and/or other	5	(7.2)	2	(5.8)	2	(8.7)	1	(7.7)
carrying out of the end-of-life decision:								
Not involved†	7	(10.1)	4	(12.1)	2	(8.7)	1	(7.7)
Practical preparation†	45	(65.2)	24	(72.7)	14	(60.9)	7	(53.8)
Present at the implementation:								
to assist the physician‡	40	(58.8)	24	(75.0)	10	(43.5)	6	(46.2)
to support patient and/or family‡	52	(76.5)	26	(81.3)	17	(73.9)	9	(69.2)
Implementation of the ELD:§								
Physician present†	32	(46.4)	17	(51.5)	7	(30.4)	8	(61.5)
Physician not present‡	10	(14.7)	1	(3.0)	5	(22.7)	4	(30.8)

* It concerned the nurse him/herself or a colleague-nurse.
† One case was missing.
‡ Two cases were missing.
§ In two cases the nurse indicated that the physician was present and not present.

Nurses' attitudes towards end-of-life decisions

The nurses agreed strongly with the statements that pointed to the possibility of forgoing a treatment (**Table 6**). Most of the nurses agreed that continuation of treatment is not always in the interests of the child (90%) and that forgoing treatment is justified in some cases (92%). As for nurses' attitudes about decision making, they agreed strongly that considerations about expected quality of life should be taken into account in decision making, and most nurses thought that parents should be involved in the decision making. Nurses reported that they are willing to cooperate in the administration of lethal drugs, slightly more than are willing to administer the lethal drugs by themselves. Only a minority (6%) found it always ethically wrong to hasten the death of a child by administering lethal drugs. Most nurses working in a PICU thought that the law should be adapted, making life termination of children legally possible in some cases (**Table 6**).

Table 6 - Attitudes of pediatric intensive care nurses towards medical end-of-life decisions in children (N = 89)

Statement	no. (%) Agree or strongly agree	Neutral	Disagree or strongly disagree
1. There is an ethical difference between the forgoing of treatment and the administering of drugs, even when both cause the death of the child.*	63 (72.4)	14 (16.1)	10 (11.5)
2. I would not participate in any form of life termination of children.	5 (5.6)	12 (13.5)	72 (80.9)
3. In some cases forgoing treatment is justified.	82 (92.1)	1 (1.1)	6 (6.7)
4. It is always ethically wrong to hasten the death of a child by administering lethal drugs.	5 (5.6)	18 (20.2)	66 (74.2)
5. The physician should discuss treatment withdrawal with the parents.	70 (78.7)	14 (15.7)	5 (5.6)
6. In some cases treatment provided to a child with a serious disorder is undesirable.†	48 (54.5)	25 (28.4)	15 (17.0)
7. In some cases, I would be prepared to shorten the terminal suffering of a child by administering lethal drugs.	61 (68.5)	14 (15.7)	14 (15.7)
8. The law should be adapted to make life termination of children in some cases possible.*	77 (88.5)	6 (6.9)	4 (4.6)
9. The task of the physician sometimes includes the prevention of unnecessary suffering by hastening death.	74 (83.1)	9 (10.1)	6 (6.7)
10. Considerations about expected quality of life should be taken into account in decision-making.	81 (91.0)	3 (3.4)	5 (5.6)
11. Due to incompetence of children, life termination is always wrong.*	7 (8.0)	15 (17.2)	65 (74.7)
12. I would involve the parents in the decision-making of seriously ill children.	66 (74.2)	16 (18.0)	7 (7.9)
13. The parents' wishes must be taken into account in decisions to forgo a treatment.	76 (85.4)	8 (9.0)	5 (5.6)
14. Continuation of treatment is not always in the interest of the child.	80 (89.9)	4 (4.5)	5 (5.6)
15. In some cases, I would be prepared to shorten the terminal suffering of a child by cooperating in the administering of lethal drugs.†	69 (78.4)	13 (14.8)	6 (6.8)

* Data missing for two cases.
† Data missing for one case.

Discussion

Most Belgian PICU nurses are confronted with end-of-life decisions with a possible or certain life-shortening effect, are often involved in carrying out such decisions, and have clear views about life termination of children in general and about administering drugs explicitly intended to hasten a child's death in particular. Our study was the first investigation of the involvement of PICU nurses in end-of-life decisions and their attitudes toward those decisions in Belgium, a country where euthanasia has been legal for adults since May 2002. Unlike most earlier studies, in which nurses' involvement was measured through physicians' reports (7;12), in our study, nurses working in PICUs were questioned in depth. Despite the illegal nature of some of the practices concerned, the response rate was rather satisfying. Nurses from 5 of a total of 7 PICUs in Belgium participated in the study, and we can assume that our results are representative of these 5 units as far as the sex, age, years of experience, and educational level of the nurses.

Our results also indicate that Belgian PICU nurses are likely to be confronted with end-of-life decisions. As found in other studies about end-of-life decisions in children (5;11), non-treatment decisions are commonly made and are often combined with the decision to intensify the pain/symptom alleviation with a possible life-shortening side effect. In the latter, death is mostly seen as an unintended consequence of appropriate care (5), attributed to the ethical principle of double effect, whereas non-treatment decisions are considered as letting the patient die – to undergo a natural death. In our study, however, we also found cases in which drugs that were explicitly intended to hasten death were administered to children, a practice considered illegal in Belgium.

As already reported by other investigators (18;28), we found that PICU nurses are not likely to initiate discussions of end-of-life decisions. Our finding that nurses are involved in the decision making in only half of cases is also in line with results of previous studies (7;29) suggesting that in Belgium, as elsewhere, PICU physicians do not consider nurses as important partners in end-of-life decisions. Although more intensive interdisciplinary collaboration and the involvement of the entire care team in decision making has been recommended (20-22;30), this practice is clearly not fully implemented in Belgian PICUs. Our study also indicated, however, that not all PICU nurses wanted to be involved in the decision making and that more than half of those who were not involved were satisfied with their non-involvement. Nurses do not always rate their own contributions to decision making as highly important (29).

In contrast to their limited involvement in decision making, most nurses are involved in the actual carrying out of end-of-life decisions. Similar results have been found in other studies based on physicians' or parents' opinions (18;31). Nurses mostly support the child and/or the child's family, but in more than half of cases, the nurses also assisted the physician. Our findings suggest that during the carrying out of end-of-life decisions, nurses have responsibilities to the child

and the child's parents as well as to the physician. Because the nurses are providing daily care, they are obviously involved; however, they sometimes carry out the end-of-life decision themselves and sometimes do so without the physician's presence. This finding is in accordance with results of another study (28), in which physicians were not always at the bedside when an end-of-life decision was carried out.

Most nurses think that continuation of treatment is not always in the interest of the child. This result suggests that nurses, much like physicians who care for terminally ill neonates, also subscribe to a best-interest standard (27). Nurses also accept a quality-of-life ethic, as shown by the high level of agreement on the acceptability of quality-of-life considerations. These nurses generally agreed that forgoing a treatment is justified and that hastening death could in some cases be the only option for preventing unnecessary suffering. This result is also in keeping with previous findings (28;32;33). Furthermore, nurses consider the involvement of parents in the decision to be important (27). Apparently, PICU nurses comply with international guidelines that state that decisions should be jointly made by physicians and parents (34;35).

Since 2002, euthanasia, namely the use of drugs explicitly intended to hasten death at the patient's explicit request, has been allowed under certain conditions in Belgium (13). However, euthanasia is not allowed for patients less than 18 years old, and especially not for younger children because they are considered incapable of making an informed request to their treating physician. Most nurses in this study favour an adaptation of the law, making life termination of terminally ill children possible. Nurses are confronted daily with the pain and suffering of terminally ill children. Being personally confronted with suffering could contribute to the conviction that termination of life should be a possible option for a child. We also must consider that nurses do not have to decide on terminating the life of a terminally ill child. Strong support for extending the law to minors would induce ethical concerns and discussion for those who do not currently have any decision-making capacity. Finally, we want to emphasize that at the time of our study, public and institutional debate about this topic was ongoing. Even in preparation for the current euthanasia law, the advisory committee mentioned the acceptance of life-ending acts with children who have unbearable pain (36). In 2006, an enactment was submitted to the Belgian Senate to extend the current euthanasia law to minors, but it was not accepted (37).

Our results indicate that most PICU nurses are willing to cooperate in administering drugs explicitly intended to hasten a child's death, even when the child's physician is not present. In this study, we can assume that nurses administered the lethal drugs themselves, an act that places them in a doubly vulnerable legal position: the law forbids life termination of children and explicitly states that euthanasia must be performed by a physician. In the field, nurses act under the responsibility of the physician. However, it is not clear to what extent nurses are responsible for their actions, particularly in the case of administering life-ending drugs. Nurses have the right to decline to cooperate (13). When a

nurse experiences an ethical dilemma, it is the nurse's responsibility to question the physician's directive. It is, therefore, important for nurses to be articulate to avoid moral distress when they experience it (17).

Nurses have concerns about the overuse of life-prolonging technologies and have a desire to relieve suffering. They are often dissatisfied and distressed in providing end-of-life care (38;39). The fact that nurses are actively involved in carrying out end-of-life decisions but are not always involved in the decision making may increase their moral distress.

Limitations
Although no indications suggested that the 2 units that did not participate in the study differed from the participating units in their care delivery, size, nurse characteristics, or other factors, we cannot fully exclude a potential bias in the results due to the non-participation of 2 units. Another limitation is the retrospective design of the study, probably inducing recall bias among the nurses. Because we did not gather information about the drugs used and we did not ask the involved physicians about their intentions, we cannot be fully certain whether or not physicians would classify the cases similarly (12). Nevertheless, we wanted to focus on the nurses' views and interpretation of the process of making and carrying out end-of-life decisions.

Conclusion and implications
Although their participation in decision making is somewhat limited, Belgian PICU nurses are often confronted with and involved in carrying out end-of-life decisions. Furthermore, a large majority of those nurses support a change in the law on euthanasia that would make life termination in children possible in some cases. As a large proportion of PICU nurses wanted to be involved in making end-of- life decisions, and because they are often responsible for carrying out such decisions, PICU nurses should be included in the making of end-of-life decisions for terminally ill children. Because PICU nurses also have clear views about end-of-life decisions with terminally ill children, the nurses also should be heard in the public debate on these decisions in general and on extending the current euthanasia law to minors in particular. Our study should prompt nurses, physicians, and other health care professionals in all countries to examine their practices related to end-of-life decisions with children more openly and collaboratively. These findings have implications for nursing and medical education. A clear assignment of responsibilities and discussion of the importance of open communication in end-of-life care should be part of the training of nurses and physicians, and more research should be conducted in this important area, particularly related to end-of-life decisions in minors.

Acknowledgements

We thank all participating nurses from the PICUs who provided data for this study. The Fund for Scientific Research in Flanders, Belgium, provided financial support.

References

(1) Kuhse H, Singer P, Baume P, Clark M, Rickard M. End-of-life decisions in Australian medical practice. Med J Aust 1997; 166(4):191-196.
(2) Meier DE, Emmons CA, Wallenstein S, Quill T, Morrison RS, Cassel CK. A national survey of physician-assisted suicide and euthanasia in the United States. N Engl J Med 1998; 338(17):1193-1201.
(3) Deliens L, Mortier F, Bilsen J, et al. End-of-life decisions in medical practice in Flanders, Belgium: a nationwide survey. Lancet 2000; 356(9244):1806-1811.
(4) van der Heide A, Deliens L, Faisst K, et al. End-of-life decision-making in six European countries: descriptive study. Lancet 2003; 362(9381):345-350.
(5) Burns JP, Mitchell C, Outwater KM, et al. End-of-life care in the pediatric intensive care unit after the forgoing of life-sustaining treatment. Crit Care Med 2000; 28(8):3060-3066.
(6) Garros D, Rosychuk RJ, Cox PN. Circumstances surrounding end of life in a pediatric intensive care unit. Pediatrics 2003; 112(5):e371-e379.
(7) Devictor DJ, Nguyen DT. Forgoing life-sustaining treatments: how the decision is made in French pediatric intensive care units. Crit Care Med 2001; 29(7):1356-1359.
(8) van der Wal ME, Renfurm LN, van Vught AJ, Gemke RJ. Circumstances of dying in hospitalized children. Eur J Pediatr 1999; 158(7):560-565.
(9) Copnell B. Death in the pediatric ICU: caring for children and families at the end of life. Crit Care Nurs Clin North Am 2005; 17(4):349-360.
(10) Althabe M, Cardigni G, Vassallo JC, et al. Dying in the intensive care unit: collaborative multicenter study about forgoing life-sustaining treatment in Argentine pediatric intensive care units. Pediatr Crit Care Med 2003; 4(2):164-169.
(11) McCallum DE, Byrne P, Bruera E. How children die in hospital. J Pain Symptom Manage 2000; 20(6):417-423.
(12) Vrakking AM, van der Heide A, Arts WF, et al. Medical end-of-life decisions for children in the Netherlands. Arch Pediatr Adolesc Med 2005; 159(9):802-809.
(13) Belgian Ministry of Justice. The Belgian Euthanasia Act [in Dutch]. Belgian Law Gazette of June 22; 2002.
(14) Crain N, Dalton H, Slonim A. End-of-life care for children: bridging the gaps. Crit Care Med 2001; 29(3):695-696.
(15) Carter BS, Howenstein M, Gilmer MJ, Throop P, France D, Whitlock JA. Circumstances surrounding the deaths of hospitalized children: opportunities for pediatric palliative care. Pediatrics 2004; 114(3):e361-e366.
(16) Harbaugh BL, Tomlinson PS, Kirschbaum M. Parents' perceptions of nurses' caregiving behaviors in the pediatric intensive care unit. Issues Compr Pediatr Nurs 2004; 27(3):163-178.
(17) Mekechuk J. Moral distress in the pediatric intensive care unit: the impact on pediatric nurses. Leadersh Health Serv 2006; 19(4-5):i-vi.
(18) Meyer EC, Burns JP, Griffith JL, Truog RD. Parental perspectives on end-of-life care in the pediatric intensive care unit. Crit Care Med 2002; 30(1):226-231.
(19) Trovo de Araujo MM, Paes da Silva MJ. Communication with dying patients: perception of intensive care units nurses in Brazil. J Clin Nurs 2004; 13(2):143-149.
(20) Burns JP, Rushton CH. End-of-life care in the pediatric intensive care unit: research review and recommendations. Crit Care Clin 2004;20(3):467-485.
(21) Browning DM, Solomon MZ. The initiative for pediatric palliative care: an interdisciplinary educational approach for healthcare professionals. J Pediatr Nurs 2005; 20(5):326-334.
(22) Truog RD, Meyer EC, Burns JP. Toward interventions to improve end-of-life care in the pediatric intensive care unit. Crit Care Med 2006; 34(11 Suppl):S373-S379.
(23) Groot-Bollujt W, Mourik M. Bereavement: role of the nurse in the care of terminally ill and dying children in the pediatric intensive care unit. Crit Care Med 1993; 21(6 Suppl):S391-S392.
(24) Nipshagen MD, Polderman KH, DeVictor D, Gemke RJ. Pediatric intensive care: result of a European survey. Intensive Care Med 2002; 28(12):1797-1803.
(25) Lesandré M. Intensive care for children: programme and architectonic, organisational, and functional aspects [in Dutch]. Brussels; 2001.

(26) Mortier F, Bilsen J, Vander Stichele RH, Bernheim J, Deliens L. Attitudes, sociodemographic characteristics, and actual end-of-life decisions of physicians in Flanders, Belgium. Med Decis Making 2003; 23(6):502-510.
(27) Provoost V, Cools F, Mortier F, et al. Medical end-of-life decisions in neonates and infants in Flanders. Lancet 2005; 365(9467):1315-1320.
(28) Burns JP, Mitchell C, Griffith JL, Truog RD. End-of-life care in the pediatric intensive care unit: attitudes and practices of pediatric critical care physicians and nurses. Crit Care Med 2001; 29(3):658-664.
(29) Street K, Ashcroft R, Henderson J, Campbell AV. The decision making process regarding the withdrawal or withholding of potential life-saving treatments in a children's hospital. J Med Ethics 2000; 26(5):346-352.
(30) Hilden JM, Emanuel EJ, Fairclough DL, et al. Attitudes and practices among pediatric oncologists regarding end-of-life care: results of the 1998 American Society of Clinical Oncology survey. J Clin Oncol 2001; 19(1):205-212.
(31) Cremer R, Binoche A, Noizet O, et al. Are the GFRUP's recommendations for withholding or withdrawing treatments in critically ill children applicable? Results of a two-year survey. J Med Ethics 2007; 33(3):128-133.
(32) Solomon MZ, Sellers DE, Heller KS, et al. New and lingering controversies in pediatric end-of-life care. Pediatrics 2005; 116(4):872-883.
(33) Keenan HT, Diekema DS, O'Rourke PP, Cummings P, Woodrum DE. Attitudes toward limitation of support in a pediatric intensive care unit. Crit Care Med 2000; 28(5):1590-1594.
(34) American Academy of Pediatrics Committee on Bioethics. Ethics and the care of critically ill infants and children. Pediatrics 1996; 98(1):149-152.
(35) American Academy of Pediatrics Committee on Bioethics. Guidelines on foregoing life-sustaining medical treatment. Pediatrics 1994; 93(3):532-536.
(36) Advisory Committee Bio-ethics. Advice n° 9 (22 February 1999) concerning life-ending actions with incompetent patients [in Dutch]. Available at: https://portal.health.fgov.be/portal/page?_pageid=56,8546420&_dad=portal&_schema=PORTAL
(37) Belgian Senate. Enactment to supplement the law of 28 May 2002 about euthanasia concerning minors [in Dutch]. 2006. Available at: http://www.senate.be/www/webdriver?MItabObj=pdf&MIcolObj=pdf&MInamObj=pdfid&MItypeObj=application/pdf&MIvalObj=50335661
(38) Asch DA. The role of critical care nurses in euthanasia and assisted suicide. N Engl J Med 1996; 334(21):1374-1379.
(39) Elpern EH, Covert B, Kleinpell R. Moral distress of staff nurses in a medical intensive care unit. Am J Crit Care 2005; 14(6):523-530.

Part III

The involvement of nurses in end-of-life practices

Chapter 5

Assisted dying under the euthanasia law in Belgium: involvement of nurses by physicians

Johan Bilsen, **Els Inghelbrecht**, Kenneth Chambaere, Joachim Cohen, Freddy Mortier, Luc Deliens

This paper has been submitted.

To the editor

In 2002, Belgium legalised euthanasia under strict conditions of careful practice (1). Among other things, the euthanasia law stipulates that only physicians are allowed to perform euthanasia, and only after consultation of the nursing team involved in the care for the patient. In 2007, we conducted a first population-based survey on medical end-of-life practices after the enactment of the euthanasia law, allowing us to assess to what extent physicians follow these specific stipulations (2).

As in 1998 and 2001, we conducted a death-certificate study in Flanders, the Dutch speaking part of Belgium. We drew a 20% random sample of all deaths occurring between June 1st and November 30th in 2007, and mailed each of the 6927 certifying physicians an anonymous questionnaire about medical end-of-life practices. Concerning their cooperation with nurses, we asked whether physicians had previously discussed end-of-life practices with a nurse, and whether a nurse had administered life-ending drugs. Detailed information about the study protocol can be found elsewhere (3).

The response rate was 58.4%. All cases of euthanasia or physician-assisted suicide in nursing homes, 58.6% of cases in hospitals, and 44.4% of cases at home were discussed by the attending physician with nurses. A nurse administered the lethal drugs in 43.4% of the euthanasia cases in hospitals, in 13.5 % of cases at home, but in none of the cases in nursing homes. Life-ending without the patient's explicit request was discussed with nurses in 62.5% of cases in nursing homes, in 41.9% of cases in hospitals and in 16.7% of cases at home, and nurses administered the lethal drugs in respectively 25.0%, 61.4% and 27.3% of the cases. Except for life-ending without patient's explicit request, physician's consultation rate of a nurse tended to be higher in 2007 than in 1998 in all medical end-of-life decisions and in all settings, especially at home. Lethal drug administration by nurses tended to occur less often in 2007 compared with 1998, especially in institutes.

Five years after the enactment of the euthanasia law in Belgium, physicians –in breach of that law- still quite often delegate the administration of lethal drugs to nurses, especially in hospitals. Their consultation of nurses in medical end-of-life practices remains rather suboptimal in all settings. Although physicians tend to act more carefully with regard to nurses' involvement since the euthanasia law, legal regulations probably need to be refined and, as in the Netherlands, supplemented with professional guidelines to be effective (4).

Ethics Committee Approval

Ethical approval was received from the Ethical Review Board of the University Hospital of the Vrije Universiteit Brussel and the Ethics Committee of the University Hospital of Ghent University.

Table 1 - Involvement of nurses in physician-assisted death and other medical end-of-life practices in Belgium 1998 and 2007*

	All settings		Nursing home		Hospital		Home	
Year	1998	2007	1998	2007	1998	2007	1998	2007
Euthanasia or Physician-assisted suicide† – no. (incidence %)	25 (1.2)	142 (2.0)	3 (0.6)	7 (0.2)	8 (0.9)	39 (1.7)	14 (2.5)	93 (4.2)
Discussion of practice with a nurse – %	30.4	53.5	50.0	100	40.0	58.6	25.0	44.4
A nurse administered the lethal drugs‡ – %	40.0	26.8	0	0	70.0	43.4	25.0	13.5
Ending of life without patient's explicit request† – no. (incidence %)	60 (3.2)	66 (1.8)	14 (3.0)	11 (1.0)	23 (3.0)	32 (2.4)	20 (3.6)	22 (1.4)
Discussion of practice with a nurse – %	42.6	40.0	63.6	62.5	53.1	41.9	12.5	16.7
A nurse administered the lethal drugs‡ – %	69.0	52.3	80.0	25.0	84.4	61.4	26.7	27.3
Intensified alleviation of pain and symptoms – no. (incidence %)	332 (18)	1248 (27)	79 (17)	275 (29)	144 (19)	409 (25)	99 (18)	522 (28)
Discussion of practice with a nurse – %	44.6	49.7	64.8	69.3	46.5	47.6	23.4	36.0
Withholding or withdrawing life-prolonging treatment – no. (incidence %)	303 (16)	568 (17)	92 (20)	162 (20)	145 (18)	282 (22)	63 (11)	114 (7.6)
Discussion of practice with a nurse – %	45.5	54.5	62.1	61.5	46.7	53.5	22.0	35.7
All medical end-of-life practices that possibly or certainly hastened death – no. (incidence %)	720 (39)	2025 (48)	188 (41)	455 (49)	320 (42)	762 (51)	196 (35)	751 (41)
Discussion of this practice with a nurse – %	44.4	51.2	63.2	66.0	46.8	50.2	21.4	36.3

*All percentages were adjusted for characteristics of deaths (age and sex of the patient and province, place and cause of death), and for stratification (only in 2007: according to the underlying cause of death as indicated on the death certificate and the estimated corresponding likelihood of an end-of-life decision having been made). The figures of the 2001-study were not included in the table because they were gathered during the tumultuous period of political and public debate concerning the research topic (due to the ongoing legalisation process of euthanasia in Belgium); Significant difference between 1998 and 2007 in the frequency of involvement of nurses are underlined ($P<0.05$, with the use of Fisher's Exact test).

†Euthanasia refers to the administration of lethal drugs with the explicit intention of ending the patient's life, at his or her explicit request; Physician-assisted suicide refers to the prescription or supply of lethal drugs with the intention of enabling the patient to end his or her life (occurred in 3 cases in 1998 and in 5 cases in 2007); Ending of life without patient's explicit request refers to the administration of lethal drugs without the patient's explicit request.

‡Nurse administered the drugs alone or together with the physician; in euthanasia or physician-assisted suicide in a hospital occurring in 1998, the nurse administered the drugs in the context of a palliative team in four cases, in 2007 this occurred once.

References

(1) Deliens L, van der Wal G. The euthanasia law in Belgium and the Netherlands. Lancet 2003; 362(9391):1239-1240.
(2) Bilsen J, Cohen J, Chambaere K, Pousset G, Onwuteaka-Philipsen BD, Mortier F, Deliens L. Medical end-of-life practices under the euthanasia law in Belgium. N Engl J Med 2009; 361(11):1119-1121.
(3) Chambaere K, Bilsen J, Cohen J, Pousset G, Onwuteaka-Philipsen B, Mortier F, Deliens L. A post-mortem survey on end-of-life decisions using a representative sample of death certificates in Flanders, Belgium: research protocol. BMC Public Health 2008; 8:299.
(4) van Bruchem- van de Scheur GG, van der Arend AJG, HuijerAbu-Saad H, Spreeuwenberg C, van Wijmen FCB, ter Meulen RHJ. The role of nurses in euthanasia and physician-assisted suicide in The Netherlands. J Med Ethics 2008; 34(4):154-158.

Chapter 6

Factors related to the involvement of nurses in medical end-of-life decisions in Belgium: a death certificate study

Els Inghelbrecht, Johan Bilsen, Freddy Mortier, Luc Deliens

Published in International Journal of Nursing Studies 2008; 45(7): 1022-31.

Abstract

Background Although nurses play an important role in end-of-life care for patients, they are not systematically involved in end-of-life decisions with a possible or certain life-shortening effect (ELDs). Until now we know little about factors relating to the involvement of nurses in these decisions.
Objective To explore which patient- and decision-characteristics are related to the consultation of nurses and to the administering of life-ending drugs by nurses in actual ELDs in institutions and home care, as reported by physicians.
Method We sampled at random 5005 of all registered deaths in the second half of 2001 – before euthanasia was legalized – in Flanders, Belgium. We mailed anonymous questionnaires to physicians who signed the death certificates and asked them to report on ELDs, including nurses' involvement.
Results Response rate was 59% (n = 2950). Physicians reported nurses involved in decision making more often in institutions than at home, and more often in care homes for the elderly than in hospitals (OR 1.70, 95% CI 1.15, 2.52). This involvement was more frequently when physicians intended to hasten the patient's death than when they had no such intention (institutions: OR 2.05, 95% CI 1.41, 2.99; home: OR 2.04, 95% CI 1.19, 3.49). In institutions, this involvement was also more likely where patients were of lower rather than higher education (OR 2.95, 95% CI 1.49,5.84). The administering of life-ending drugs by nurses, as reported by physicians was also found more frequently in institutions than at home, and in institutions more frequently with lower rather than higher educated patients (p = .037).
Conclusions These findings raise questions about physicians' perception of the nurse's role in ELDs, but also about physicians' skills in interacting with all patients. Education and guidelines for physicians and nurses are needed to optimize good communication and to promote a clearer assignment of responsibilities concerning the execution of those decisions.

Introduction

Research in many different countries has shown that end-of-life decisions with a possible or certain life-shortening effect (ELDs) are common in medical practice (1-5). These ELDs can be classified as withholding or withdrawing a probably life-prolonging treatment, pain and/or symptom alleviation with a possible life-shortening effect, and the use of drugs with the explicit intention of hastening the patient's death. As in other medical decisions, patients and physicians are considered to be formally responsible for ELDs, but the involvement of other healthcare professionals is usually inevitable and is often considered to be indispensable to good care for those near the end of life (6-8).

Nurses care for patients on a daily basis and are usually well informed about the situation and needs of patients and relatives. Furthermore, as the physician's closest co-workers in the field they are often entrusted with carrying out the physician's orders, which may include end-of-life practices (6;9-11). Nevertheless, the literature reveals that, predominantly, physicians make ELDs alone or in collaboration with colleague–physicians (12-14), and nurses are not systematically involved in the decision-making process which precedes these ELDs (15-19). On the other hand, the participation of nurses in the administering of life-ending drugs can be considered substantial, taking into account the illegality of these acts (2;16;17;20;21). Until now little is known about which factors relate to whether or not nurses are involved in these decisions, be it in the decision-making process or in the administering of life-ending drugs.

Some studies have explored the influence of the physician's own social and professional characteristics on the degree to which they consult nurses (22). Others have explored the relationship between the social and professional characteristics of nurses and their participation in the administering of life-ending drugs (15;23;24). However, as far as we know, the physician's readiness to consult nurses or to delegate the actual administering of life-ending drugs to them has never been investigated in relation to the specific characteristics of the patients themselves. Neither are we aware of any study examining the relationship between the different characteristics of ELDs (e.g. withholding or withdrawing a probably life-prolonging treatment compared with the use of drugs with the explicit intention of hastening the patient's death, or the life-shortening intention of the physician) and a nurse's involvement in these decisions. A study of those associations nationwide and in all settings, based on a representative sample of all actual registered deaths, may contribute to a better and more reliable understanding of the mechanisms that determine a nurse's involvement in these decisions. This information could be very useful for optimizing nurses' involvement in ELDs, as well as for assuring good end-of-life care for all patients, irrespective of their characteristics.

Methods

Aim
The aim of this study is to explore which patient- and decision-characteristics are related to the consultation of nurses and the administering of life-ending drugs by nurses in actual ELDs in institutions as well as at home, as reported by physicians.

Design
A cross-sectional retrospective death certificate study was conducted in 2001 in Flanders, the northern Dutch speaking region of Belgium where approximately 60% of the Belgian population lives and where about 56 000 deaths occur each year (54% in hospitals, 20% in care homes for the elderly, and 24% at home) (25). The unit of analysis was the sampled death case and the information on ELDs was supplied by the physicians who signed the death certificates, via a mail questionnaire. At the time the study was performed, euthanasia was not legal in Belgium, but a law allowing it under certain conditions was under discussion (26).

Sample
All deaths in Flanders are reported to the Health Care Division of the Ministry of Flanders through death certificates. All deaths of those aged one year or older which took place between June and December 2001 (n = 26 229) were stratified for the likelihood that an ELD had preceded the patient's death. Larger samples were taken for the strata in which the cause of death had made an ELD more likely. In total, 5005 (a 20% random sample taken systematically) death certificates were drawn and anonymous questionnaires about the medical ELD-making which preceded them were mailed to the physicians who had signed these certificates. To enhance the response rate, the survey was conducted by the principles of the Total Design Method (27), including three follow-up mailings in case of non-response. More details about the mailing procedure and methodology are reported elsewhere (5).

Questionnaire
The first part of a four-page questionnaire asked about medical interventions with a possible or certain life-shortening effect. These questions did not contain words like 'euthanasia' or 'physician-assisted suicide' to avoid possible confusion and ethical connotations. Instead, the actual medical practices were described and classified in accordance with robust previous studies on ELDs (1;4;5) into three main ELD-categories:

(a) Non-treatment decision: Withholding or withdrawing a probably life-prolonging medical treatment while taking into account the possibility that this would hasten the patient's death or with the explicit intention of hastening the patient's death.

(b) Alleviation of pain and/or other symptoms: Intensifying pain and/or symptom alleviation while taking into account the possibility that this would

hasten the patient's death or with the co-intention of hastening the patient's death.
(c) Physician-assisted dying: Using life-ending drugs with the explicit intention of hastening the patient's death.

We considered a case as euthanasia, only when these drugs were administered at the explicit request of the patient; as physician-assisted suicide, when the patient had taken the drug him/herself; or, as life-ending acts without the patient's explicit request, when the drugs were administered without the explicit request of the patient. To determine the administering of drugs by nurses in those cases where life-ending drugs had been used, we asked: 'Who had administered these drugs?' with possible answers: 'the patient him/herself, the physician him/herself or a colleague-physician, the nursing team, or someone else'. If more than one ELD was reported for one patient, the decision with the most explicit life-shortening intention prevailed over the others, and in case of similar intention, physician-assisted dying prevailed over alleviation of pain and/or symptoms, and the latter prevailed over non-treatment decision.

In the second part of the questionnaire, we further asked the physician to estimate the length of time by which life had been shortened as a consequence of the ELD and to answer the questions about the decision-making process. To investigate the consultation of nurses, we asked: 'Did you or another physician discuss the (potential) life-shortening effect of the decision with other caregivers?' Multiple answers were possible: 'with one or more colleague-physician, with the nursing team, with someone else, or with nobody'.

At the end of the study, information about the deceased patient on the death certificate (e.g. sociodemographic factors, cause of death, and place of death) was linked to the questionnaires and provided to the researchers under conditions of anonymity.

Ethical considerations

A complex mailing procedure, approved by the Belgian National Disciplinary Board of physicians and supervised by a legal attorney, was developed to assure anonymity for physician and patient. The study was also approved by the Ethical Review Board of the Academic Hospital of the Vrije Universiteit Brussel (Brussels, Belgium).

Data analysis

All data were adjusted for the disproportional stratification of the sample and weighted for non-response bias in patient characteristics (sex, age, place of death, and cause of death), according to all deaths in Flanders, during the studied period. More details on stratification and weighting procedures have been published elsewhere (5). Due to differences between institutional and home care, both in the organization of the care and in the role of nurses in caring for terminally ill patients (16;17), analyses were made separately for home deaths and institution deaths. Results for physician-assisted suicide and euthanasia were combined because only one case of physician-assisted suicide had been

observed. A frequency distribution was presented to describe the demographic data of the sample and the consultation of nurses and the delegation of administering life-ending drugs to nurses in the different ELDs. Fisher's exact tests were used to compare deaths occurring in institutions and at home on patient characteristics and to explore whether patient- and decision-characteristics were related to the consultation of nurses in ELDs and the administering of life-ending drugs by nurses. To explore whether patient- and decision-characteristics were independently related to the consultation of nurses, we used multiple logistic regression analyses. For the institution deaths, care homes for the elderly vs. hospitals was also included in the model as an independent factor. All p values were based on two-sided tests (5% a-level) and analyses were performed with the statistical packages StatXact 6 and SPSS 12.0.

Results

The response rate was 59% (n = 2950). In 38.5% of all deaths (n = 1354), death was preceded by at least one ELD: withholding or withdrawing a probably life-prolonging medical treatment were reported in 14.6%, alleviation of pain and/or symptoms with a possible life-shortening effect in 22.1%, the use of drugs with the explicit intention of hastening the patient's death at the patient's explicit request (euthanasia) occurred in 0.3%, and without the patient's explicit request in 1.5% of all deaths in Flanders (5).

Table 1 - Characteristics of deaths preceded by an end-of-life decision in an institution and at home, in Flanders, 2001

Patient characteristics	All ELDs* *n = 1354*	Institution *n = 878*	Home *n = 470*	*p* value†
Sex				<0.001
Female	50.6	53.6	40.4	
Male	49.4	46.4	59.6	
Age (years)‡				<0.001
≤ 80	54.9	51.1	68.0	
>80	45.1	48.9	32.0	
Education				<0.001
Primary education or lower	44.0	47.4	33.0	
Lower and higher secondary	29.5	27.3	37.2	
Higher education and university	5.0	4.5	6.9	
Unknown§	21.5	20.9	23.0	
Cause of death				<0.001
Malignancies	42.9	35.2	69.9	
Cardiovascular diseases	18.8	21.0	11.5	
Respiratory diseases	9.5	11.2	3.7	
Diseases of the nervous system (incl. CVA)	12.8	14.5	7.1	
Other	16.0	18.2	7.8	

Data are weighted %. Percentages were adjusted for stratification and weighted for non-response compared to all deaths in Flanders, 2001.
* Five deaths occurred not at home, neither in an institution. One death had a missing value for place of death.
† For all patient characteristics, differences in distribution between end-of-life decisions in an institution and end-of-life decisions at home were tested, using Fisher's exact test.
‡ One case was missing.
§ Not included in significance test.

Patient characteristics

Of all 1354 deaths preceded by at least one ELD, 878 (77.1%) occurred in an institution compared to 470 (22.5%) at home (**Table 1**). About half of those deaths concerned female patients (50.6%) and almost half of those deaths, patients were older than 80 years (45.1%). A small proportion of the patients had achieved higher education (5.0%) and many patients suffered from cancer (42.9%). Compared with ELD deaths in an institution, ELD deaths at home included more male patients (59.6% vs. 46.4%), more patients younger than 80 years (68.0% vs. 51.1%), fewer patients with primary or lower education (33.0% vs. 47.7%), and more patients suffering from cancer (69.9% vs. 35.2%).

Involvement of nurses

Consultation of nurses

Before making an ELD, nurses were consulted by the reporting physicians more often in institutions (67.8%) than at home (39.0%) (**Table 2**). In both settings, this consultation was highest in the case of physician-assisted dying (74.1% and 47.9%, respectively, for institution and home deaths) followed by non-treatment decisions (70.9% and 44.5%) and was lowest in the case of intensification of pain and/or symptom alleviation (64.8% and 35.2%). However, for both settings, we found no statistical differences for the consultation of nurses according to ELD type.

Table 2 - Involvement of nurses in end-of-life decisions in an institution and at home

	Institution		Home	
	no.	Nurses' consulted %*	no.	Nurses' consulted %*
All end-of-life decisions†	878	67.8	470	39.0
- Alleviation of pain and/or symptoms	519	64.8	325	35.2
- Non-treatment decisions	323	70.9	107	44.5
- Physician assisted dying	36	74.1	38	47.9
- Euthanasia‡	4	100.0	12	41.1
- Life-ending acts without patient's explicit request	32	71.7	26	50.9
	no.	Nurses' administering drugs %*	no.	Nurses' administering drugs %*
- Physician assisted dying§	36	66.9	38	30.0
- Euthanasia‡	4	47.7	12	32.7
- Life-ending acts without patient's explicit request	32	68.7	26	28.8

Missing cases: End-of-life decisions: Institution: 56 cases; Home: 32 cases. Alleviation of pain and/or symptoms: Institution: 48 cases; Home: 31 cases. Non-treatment decisions: Institution: 8 cases; Home: 1 case.
* Data are weighted %. Percentages are adjusted for stratification and weighted for non-response.
† Differences in nurses' consulted % between the type of end-of-life decision and all other types of end-of-life decisions were tested, using Fisher's exact test. No statistical significant differences were found.
‡At home, in 1 case the patient had administered the life-ending drug by him/herself.
§ Differences in nurses' administering drugs % between euthanasia and life-ending acts without the patient's explicit request were tested, using Fisher's exact test. No statistical significant differences were found.

Administering of life-ending drugs by nurses

According to the reporting physicians, nurses administered drugs in 66.9% of those cases where drugs were administered with the explicit intention of hastening the patient's death in an institution and in 30.0% at home (**Table 2).** This difference was statistically significant. In institutions, nurses tended to administer life-ending drugs more often in cases of life-ending acts without the patient's explicit request (68.7%) than in cases of euthanasia (47.7%). However, this difference is not statistically significant. Also at home, we found no significant differences between euthanasia (32.7%) and life-ending acts without the patient's explicit request (28.8%).

Factors relating to the involvement of nurses

Consultation of nurses

In an institution, nurses are more often consulted by physicians before making an ELD in the case of patients with lower levels of education (higher secondary or lower) than of those with higher education (higher education or university), in the case of patients dying in a care home for the elderly rather than in hospital, and in those cases where the physician intended to hasten the patient's death as opposed to those where there was no such intention (**Table 3**). The results of these bivariate comparisons were confirmed in logistic regression which investigated the relation of each characteristic independently. Physicians were 3 times more likely to consult a nurse with patients of lower rather than higher education (OR = 2.95, 95% CI 1.49, 5.84), nearly 2 times more likely in a care home for the elderly than in a hospital (OR = 1.70, 95% CI 1.15, 2.52) and 2 times more likely when the physician intended to hasten the patient's death than without this intention (OR = 2.05, 95% CI 1.41, 2.99).

For ELD-deaths occurring at home, physicians were also 2 times more likely to consult nurses in the case of decisions intended to hasten the patient's death as opposed to those without such intention (OR = 2.04, 95% CI 1.19, 3.49).

Administering of life-ending drugs by nurses (data not shown in table)

In deaths at home, we found no significant relationship between patient- or decision-characteristics and the administering of life-ending drugs by nurses. In institutions, nurses administered the life-ending drugs more often when the patient had lower (higher secondary or lower) rather than higher levels of education (higher education or university) (74.1% vs. 20.0%; p = .037). Due to the low number of cases of physician-assisted dying, logistic regression analysis was not performed.

Table 3 - Patient- and decision-characteristics related with the consultation of nurses in end-of-life decisions in an institution and at home

	Institution *n=822*				Home *n=438*			
	n	Nurses' consulted %*	*p* value†	OR (95% CI)‡	n	Nurses' consulted %*	*p* value†	OR (95% CI)‡
Patient characteristics								
Sex			0.408				0.178	
Female	436	69.2			159	44.2		
Male	386	66.3			279	35.4		
Age			0.601				0.119	
≤ 80	444	66.9			326	35.6		
>80	378	68.7			112	46.8		
Education§			**0.011**				0.425	
No higher education	602	68.9		2.95 (1.49-5.84)	309	38.3		
Higher education	38	47.4			26	50.0		
Place of death			**0.001**					
Care home for the elderly	263	76.4		1.70 (1.15-2.52)				
Hospital	559	64.4						
Cause of death			0.136				0.252	
Malignancies	417	64.5			372	36.4		
No malignancies	405	69.8			66	44.6		
Patient competent at time of decision			0.775				0.267	
Yes	197	69.1			181	36.7		
No	582	70.3			219	44.6		
Decision characteristics								
Type of ELD			0.155				0.290	
Non-treatment decisions	323	70.9			107	44.5		
Alleviation of pain and/or symptom	519	64.8			325	35.2		
Physician assisted dying	36	74.1			38	47.9		
Life-shortening intention			**<0.001**				**0.009**	
Yes	289	76.9		2.05 (1.41-2.99)	155	50.0		2.04 (1.19-3.49)
No	533	62.6			283	32.7		
Estimated amount of time by which life was shortened			0.210				0.850	
Less than 1 week	687	68.9			350	42.2		
One week and more	101	75.2			61	39.4		

* Data are weighted %. Percentages are adjusted for stratification and weighted for non-response.
† Differences in distribution of the different patient- and decision-characteristics for the consultation of nurses are tested, using Fisher's exact test. Statistical significant differences are indicated in bold.
‡ Multivariate testing, using logistic regression. Only significant OR's are presented: OR indicates odds ratio; CI, confidence interval. ORs>1.00 indicates that the consultation of nurses is more likely in the category given.
§ No higher education: higher secondary and lower; Higher education: higher education and university.

Discussion

As in previous studies (16;17), in this study nurses are consulted more frequently in an institution than they are at home. Additionally, we find that within institutions, nurses are consulted more frequently in care homes for the elderly than in hospitals. In care homes for the elderly, nurses provide supervision of and assistance in the daily activities of the residents and have great responsibility in the administering of treatments. They work autonomously and mostly in teams which consist predominantly – and sometimes solely – of nurses and some other paramedic carers. In Belgium, a physician is not part of the team responsible for the care of residents, though a general practitioner (GP) provides medical assistance. GPs depend greatly on these nurses for their profound knowledge of the patient and their medical expertise, including their contribution to good end-of-life care. In hospitals, nurses work in an extended multidisciplinary team with clinical specialists in a leading role. Clinical specialists and nurses participate in the systematic team discussions that take place at regular intervals. However, this study shows that those physicians not always use the consultative structure, embedded in the hospital, before making an ELD, although nurses are regarded as key figures in informing clinical specialists about the patient's health status (28) and have clear views on ELDs (9;29). It can be hypothesized that colleague-physicians partly replace nurses as consultants, as can be found in Deliens et al. (4) and Bilsen et al. (30). In home care, nurses are least frequently consulted by physicians. Terminally ill patients staying at home are medically treated by their GP who often works alone. At least a part of terminal care at home is likely to be provided by close relatives. When the care is too burdensome for informal caregivers, homecare nurses can be called in (31). In general those nurses have very strict working schedules and work within a system of shifts consisting of different nurses. In Belgium, intensive interdisciplinary group discussions between the GP and homecare nurses are not likely to occur.

Due to the lower levels of interaction between GPs and homecare nurses and the absence in homecare of a structural interdisciplinary consultation culture, delegation of tasks, in this case the administering of life-ending drugs, to nurses is also less obvious. However, the current study reveals that in about one-third of the cases, homecare nurses administer life-ending drugs. This is for nurses illegal to perform. However, other studies have confirmed that homecare nurses do sometimes administer life-ending drugs. It may be hypothesized that physicians delegate this task to nurses, although it remains under their responsibility. Perhaps, physicians consider nurses more technically experienced to administer life-ending drugs (16;17). At home, administering life-ending drugs can also be performed clandestinely. The question should be raised as to whether privacy and the lack of control in the home contributes to the fact that nurses perform life-ending acts. In institutions, the performance of life-ending acts by nurses is even higher. In institutions, it is more common practice that tasks supported by team decisions are delegated to nurses. Nonetheless, this study raises ethical concerns about the fact that even such decisive acts are

easily delegated to nurses, which places nurses in a legally insecure situation. For both settings, there are no differences in nurses' involvement in euthanasia as compared with life-ending acts without the patient's explicit request. The latter mostly occurs with patients who were rated as not being able to be involved in the decision-making (32;33). In those cases, healthcare professionals act in a manner they deemed appropriate. This study confirms that the patient's competence neither influences the physician's consultation of nurses, nor the physician's delegation of the administering of life-ending drugs to nurses.

As for the results concerning the factors related to the involvement of nurses, following conclusions can be made. Firstly, when exploring the physician's readiness to consult nurses before making an ELD, we discover no significant differences according to the act performed in the ELD as such (administering drugs, withdrawing or withholding life-prolonging treatment,...), but this consultation is clearly more frequent when the physician acts with the (co-)intention of hastening the patient's death in comparison with no such decisions. Some hypotheses can be proposed pertaining to this finding. First, when making a decisive decision to hasten the patient's death, physicians may need more communication with and support from nurses, who are the patient's closest carers than with ELDs where life-shortening is only taken into account. Another possibility is that physicians prefer to share responsibility in those cases that are legally and ethically more controversial. Making decisions with a life-shortening intention adds sometimes an illegal aspect to what is otherwise perceived and accepted as medically 'normal' non-treatment or pain alleviation.

Secondly, in institutions, nurses are consulted more often by physicians and administer life-ending drugs more often when the patient is less well educated. Literature has already indicated that in general patients with a higher level of education have more skills and confidence in talking to their doctors and physicians are known to give more explanation to better-educated patients (34). Probably, physicians experience a better interpersonal contact with better educated patients who have cultural resources more like their own. It is plausible that less well-educated patients experience a sense of distance from their physician. Maybe they feel less able to communicate their needs and wishes to their physician and feel more comfortable in communicating with their more personal carers. As nurses are always present in institutions, they can act as intermediaries who narrow the gap between patients and physicians (9). This association is not found in patients dying at home. There, physicians mostly work alone and cannot always rely on other healthcare members for assistance. They are compelled to communicate with all their patients, regardless of their educational level.

A limitation of the study is that our findings are only based on the perceptions of physicians. Other perceptions, e.g. of the patient, relatives, other healthcare workers or the nurses themselves are not investigated. Research already indicated that nurses and physicians perceive their involvement in the decision-making process differently (35-37). Therefore, we could not be certain if this

reflects what truly happens, and if questioning nurses would have lead to other findings. The involvement of nurses is also explored in a rather restricted way. Nurses' role in ELDs is broader than just physicians' consultation of nurses and delegation of administering life-ending drugs to nurses (10;11;38). Furthermore, we have to take into consideration that there are large differences between countries/regions regarding physician's consultation of nurses in ELDs (5;18;19) and that these results are not entirely reflective for other populations. Nevertheless, this study provides reliable information for the whole of Flanders, not only on the incidence of actual ELD-practice and nurses' involvement in the consultation and administration of life-ending drugs in those ELDs, but also, for the first time, on the factors relating to this involvement. The current study is not restricted to a subgroup of physicians or nurses or a specific care unit/setting in healthcare (2;18-22), nor to a particular type of ELD such as euthanasia (23;24) or non-treatment decisions (15;22).

We also have to consider that both in institutions and at home, few cases of euthanasia occurred. Interpretation of the results concerning these cases should be made with caution. Albeit, most analysis were made for all ELDs together or for all cases where life-ending drugs were administered (both with and without the patient's explicit request), as there were no differences found on nurses' consultation and administering of life-ending drugs in those decisions. Furthermore, our results are based on a representative sample of real deaths and not on a random selection or hypothetical cases. The utmost care was also taken to assure total anonymity for all physicians and patients involved.
Finally, we have to bear in mind that this study was performed prior to the euthanasia law (39). However, the study provides some baseline data for later studies after euthanasia legislation. It is currently explicitly stated in the law that the patient's request has to be discussed with the involved nurses. This changing context will most likely have an influence on the physician's willingness to consult nurses. However, the law is restricted to euthanasia. The legislator had not taken the opportunity to enter the other ELDs in the present law. It is also explicitly stated that the administering of life-ending drugs has to be done only by the physician him/herself. However, both prior and after this legislation, the administering of life-ending drugs by nurses was and still is illegal. Future study – after euthanasia legislation – could possibly clear out the impact of this law on these issues.

In conclusion, this study shows that physicians are selective in involving nurses in actual medical ELDs. It is related to the patient's education level and to the impact of the ELD. It seems that physicians predominantly involve nurses concerning patients with whom they experience difficulties or concerning decisions which have serious consequences in the human as well as in the legal sphere. These findings raise questions about how physicians perceive the nurse's role in end-of-life care issues and about the physicians' skills in interacting with all patients. But it also points to the possibility of social–economical inequality in end-of-life care. We recommend that this inequality between patients, as well as the physician's perception of the nurse's role, must

be addressed to guarantee good end-of-life care for all patients. Education on communication in end-of-life care and guidelines on assigning responsibilities and optimizing communication in ELDs – applying to physicians and nurses – seem appropriate. However, additional research, especially orientated towards the role of nurses and questioning the nurses themselves, is needed to reach a more diversified, detailed and profound picture of their involvement and to understand differences between patients and healthcare settings.

Acknowledgement

The authors thank J. Vanoverloop for his statistical advice, J. Mayes for her useful comments on the article, the Federal and Flemish Ministry of Public Health for their cooperation in the data collection, all participating physicians, and all members of the EURELD consortium.

References

(1) van der Maas PJ, van der Wal G, Haverkate I et al. Euthanasia, physician-assisted suicide, and other medical practices involving the end of life in The Netherlands, 1990-1995. The New England Journal of Medicine 1996; 335(22):1699-1705.
(2) Kuhse H, Singer P, Baume P, Clark M, Rickard M. End-of-life decisions in Australian medical practice. Med J Aust 1997; 166(4):191-196.
(3) Meier DE, Emmons CA, Wallenstein S, Quill T, Morrison RS, Cassel CK. A national survey of physician-assisted suicide and euthanasia in the United States. N Engl J Med 1998; 338(17):1193-1201.
(4) Deliens L, Mortier F, Bilsen J et al. End-of-life decisions in medical practice in Flanders, Belgium: a nationwide survey. Lancet 2000; 356(9244):1806-1811.
(5) van der Heide A, Deliens L, Faisst K et al. End-of-life decision-making in six European countries: descriptive study. Lancet 2003; 362(9381):345-350.
(6) Faber-Langendoen K, Karlawish JH. Should assisted suicide be only physician assisted? University of Pennsylvania Center for Bioethics Assisted Suicide Consensus Panel. Ann Intern Med 2000; 132(6):482-487.
(7) Connor SR, Egan KA, Kwilosz DM, Larson DG, Reese DJ. Interdisciplinary approaches to assisting with end-of-life care and decision making. American Behavioral Scientist 2002; 46(3):340-356.
(8) Vincent JL. End-of-life practice in Belgium and the new euthanasia law. Intensive Care Med 2006; 32(11):1908-1911.
(9) The A. 'Vanavond om 8 uur...': Verpleegkundige dilemma's bij euthanasie en andere medische beslissingen rond het levenseinde. 1997. Houten, Bohn Stafleu Van Loghum.
(10) De Beer T, Gastmans C, Dierckx de Casterlé B. Involvement of nurses in euthanasia: a review of the literature. J Med Ethics 2004; 30(5):494-498.
(11) Dierckx de Casterlé B, Verpoort C, De Bal N, Gastmans C. Nurses' views on their involvement in euthanasia: a qualitative study in Flanders (Belgium). J Med Ethics 2006; 32(4):187-192.
(12) Vincent JL. Forgoing life support in western European intensive care units: the results of an ethical questionnaire. Crit Care Med 1999; 27(8):1626-1633.
(13) Ferrand E, Robert R, Ingrand P, Lemaire F. Withholding and withdrawal of life support in intensive-care units in France: a prospective survey. French LATAREA Group. Lancet 2001; 357(9249):9-14.
(14) Svantesson M, Sjokvist P, Thorsen H. End-of-life decisions in Swedish ICUs. How do physicians from the admitting department reason? Intensive Crit Care Nurs 2003; 19(4):241-251.
(15) Stevens CA, Hassan R. Nurses and the management of death, dying and euthanasia. Med Law 1994; 13(5-6):541-554.
(16) Muller MT, Pijnenborg L, Onwuteaka-Philipsen BD, van der Wal G, van Eijk JT. The role of the nurse in active euthanasia and physician-assisted suicide. J Adv Nurs 1997; 26(2):424-430.
(17) Bilsen JJ, Vander Stichele RH, Mortier F, Deliens L. Involvement of nurses in physician-assisted dying. J Adv Nurs 2004; 47(6):583-591.
(18) Cohen S, Sprung C, Sjokvist P et al. Communication of end-of-life decisions in European intensive care units. Intensive Care Med 2005; 31(9):1215-1221.
(19) Benbenishty J, Ganz FD, Lippert A et al. Nurse involvement in end-of-life decision making: the ETHICUS Study. Intensive Care Med 2006; 32(1):129-132.
(20) Asch DA. The role of critical care nurses in euthanasia and assisted suicide. N Engl J Med 1996; 334(21):1374-1379.
(21) Matzo ML, Emanual EJ. Oncology nurses' practices of assisted suicide and patient-requested euthanasia. Oncol Nurs Forum 1997; 24(10):1725-1732.
(22) Cardoso T, Fonseca T, Pereira S, Lencastre L. Life-sustaining treatment decisions in Portuguese intensive care units: a national survey of intensive care physicians. Crit Care 2003; 7(6):R167-R175.
(23) Kuhse H, Singer P. Voluntary euthanasia and the nurse: an Australian survey. Int J Nurs Stud 1993; 30(4):311-322.
(24) Asch DA, DeKay ML. Euthanasia among US critical care nurses. Practices, attitudes, and social and professional correlates. Med Care 1997; 35(9):890-900.

(25) Cohen J, Bilsen J, Hooft P, Deboosere P, Van der Wal G, Deliens L. Dying at home or in an institution Using death certificates to explore the factors associated with place of death. Health Policy 2005.
(26) Broeckaert B. Belgium: towards a legal recognition of euthanasia. European Journal of Health Law 2001; 8(2):95-107.
(27) Dillman DA. The Design and Administration of Mail Surveys. Annual Review of Sociology 1991; 17:225-249.
(28) van der Arend AJ. Euthanasia and assisted suicide in The Netherlands: clarifying the practice and the nurse's role. Int Nurs Rev 1998; 45(5):145-151.
(29) van Bruchem-van de Scheur A, van der Arend A, Spreeuwenberg C, van Wijmen F, ter Meulen R. De rol van verpleegkundigen bij medische beslissingen aan het levenseinde: verslag van een landelijk onderzoek naar betrokkenheid en praktijken. De Tijdstroom, Utrecht, 2004.
(30) Bilsen J, Stichele RV, Mortier F, Bernheim J, Deliens L. The incidence and characteristics of end-of-life decisions by GPs in Belgium. Fam Pract 2004; 21(3):282-289.
(31) De Vliegher K, Paquay L, Grypdonck M, Wouters R, Debaillie R, Geys L. A study of core interventions in home nursing. Int J Nurs Stud 2005; 42(5):513-520.
(32) Rietjens JA, Bilsen J, Fischer S et al. Using drugs to end life without an explicit request of the patient. Death Stud 2007; 31(3):205-221.
(33) Van den Block L, Bilsen J, Deschepper R, Van Der Kelen G, Bernheim JL, Deliens L. End-of-life decisions among cancer patients compared with noncancer patients in Flanders, Belgium. J Clin Oncol 2006; 24(18):2842-2848.
(34) Willems S, De MS, Deveugele M, Derese A, De MJ. Socio-economic status of the patient and doctor-patient communication: does it make a difference? Patient Educ Couns 2005; 56(2):139-146.
(35) Ferrand E, Lemaire F, Regnier B et al. Discrepancies between perceptions by physicians and nursing staff of intensive care unit end-of-life decisions. Am J Respir Crit Care Med 2003; 167(10):1310-1315.
(36) Thomas EJ, Sexton JB, Helmreich RL. Discrepant attitudes about teamwork among critical care nurses and physicians. Crit Care Med 2003; 31(3):956-959.
(37) Rocker GM, Cook DJ, O'callaghan CJ et al. Canadian nurses' and respiratory therapists' perspectives on withdrawal of life support in the intensive care unit. J Crit Care 2005; 20(1):59-65.
(38) De Bal N, Dierckx de Casterlé B, De Beer T, Gastmans C. Involvement of nurses in caring for patients requesting euthanasia in Flanders (Belgium): A qualitative study. Int J Nurs Stud 2006.
(39) Belgian Ministry of Justice. Wet betreffende de euthanasie (The Belgian Euthanasia Act). Belgian Law Gazette of June 22, 2002. 22-6-2002.

Chapter 7

The role of nurses in physician-assisted deaths in Belgium

Els Inghelbrecht, Johan Bilsen, Freddy Mortier, Luc Deliens

Published in the Canadian Medical Association Journal (Early release, published at www.cmaj.ca on May 17, 2010).

Abstract

Background Belgium's law on euthanasia allows only physicians to perform the act. We investigated the involvement of nurses in the decision- making and in the preparation and administration of life-ending drugs with a pa tient's explicit request (euthanasia) or without an explicit request. We also examined factors associated with these deaths.
Methods In 2007, we surveyed 1678 nurses who, in an earlier survey, had reported caring for one or more patients who received a potential life-ending decision within the year before the survey. Eligible nurses were surveyed about their most recent case.
Results The response rate was 76%. Overall, 128 nurses reported having cared for a patient who received euthanasia and 120 for a patient who received life-ending drugs without his or her explicit request. Respectively, 64% (75/117) and 69% (81/118) of these nurses were involved in the physician's decision-making process. More often this entailed an ex change of information on the patient's condition or the patient's or relatives' wishes (45% [34/117] and 51% [41/118]) than sharing in the decision-making (24% [18/117] and 31% [25/118]). The life-ending drugs were administered by the nurse in 12% of the cases of euthanasia, as compared with 45% of the cases of assisted death without an explicit re quest. In both types of assisted death, the nurses acted on the physician's orders but mostly in the physician's absence. Factors significantly associated with a nurse administering the life- ending drugs included being a male nurse working in a hospital (odds ratio [OR] 40.07, 95% confidence interval [CI] 7.37–217.79) and the patient being over 80 years old (OR 5.57, 95% CI 1.98–15.70).
Interpretation By administering the life-ending drugs in some of the cases of euthanasia, and in almost half of the cases without an explicit request from the patient, the nurses in our study operated beyond the legal margins of their profession.

Introduction

Medical end-of-life decisions with a possible or certain life-shortening effect occur often in end-of-life care (1–5). The most controversial and ethically debated medical practice is that in which drugs are administered with the intention of ending the patient's life, whether at the patient's explicit request (euthanasia) or not. The debate focuses mainly on the role and responsibilities of the physician (6). However, physicians worldwide have reported that nurses are also involved in these medical practices, mostly in the decision-making and sometimes in the administration of the life-ending drugs (1-3;7-9). Critical care (10), oncology (11), and palliative care nurses (12;13) have confirmed this by reporting their own involvement, particularly in cases of euthanasia (14;15).

In Belgium, the law permits physicians to perform euthanasia under strict requirements of due care, one of which is that they must discuss the request with the nurses involved (16). There are no further explicit stipulations determining the role of nurses in euthanasia. Physician-assisted death is legally regulated in some other countries as well (e.g., the Netherlands, Luxemburg and the US states of Oregon and Washington State), without specifying the role of nurses. Reports from nurses in these jurisdictions are scarce, apart from some that are limited to particular settings, or lack details about their involvement (13,14).

We conducted this study to investigate the involvement of nurses in Flanders, Belgium, in the decision- making and in the preparation and administration of life-ending drugs with, or without, a patient's explicit request. We also examined patient- and nurse-related factors associated with the involvement of nurses in these deaths. In a related research article, Chambaere and colleagues describe the findings from a survey of physicians in Flanders about the practices of euthanasia and assisted suicide, and the use of life- ending drugs without an explicit request from the patient (17).

Methods

Study design

In 2007, we performed a two-phase large-scale survey exploring the attitude of nurses toward end-of-life decisions with a possible or certain life-shortening effect, and their involvement in these types of decisions.

> Box 1: Three end-of-life decisions with a possible or certain life-shortening effect
> • Withholding or withdrawal of a potential life-prolonging treatment (including food and fluid).
> • Intensification of medical therapy to alleviate pain or symptoms with a possible life-shortening effect.
> • Administration of life-ending drugs with explicit intention of ending the patient's life.

The first phase was conducted between August and November 2007. It involved 6000 nurses in Flanders, Belgium, who were identified from a federal government database and asked about their attitudes toward life-shortening end-of-life decisions. The response rate of this study was 63%. More information about the characteristics of the study population and its findings is reported elsewhere.18,19 In that survey, we assessed each nurse's experience in the 12 months before the survey in caring for patients for whom life-shortening end-of-life decisions were made. We presented three types of decisions (Box 1).

A total of 1678 nurses met the inclusion criterion for the second phase of the study (see Appendix 1). In the second phase, conducted between November 2007 and February 2008, we mailed a questionnaire to these 1678 nurses with a supporting letter from two major professional nursing organizations. If necessary, a reminder letter was sent, followed by a second mailing of the questionnaire, followed by a final reminder as needed. Confidentiality of data was ensured, and all data were processed anonymously. The Ethics Committee of the University Hospital of the Vrije Universiteit Brussel granted ethical approval of the study design.

Questionnaire

The questionnaire (see Appendix 2), including the classification of the end-of-life decisions in Box 1, was based on the instrument used in incidence studies (performed among physicians) that had been proven to be valid and reliable (1-5). To translate this to nursing practice, we made adaptations to the questionnaire on the basis of one used in a Dutch study about the involvement of nurses in euthanasia14 and by testing the questionnaire extensively. Content validity was established through expert review and through an in-depth discussion by a focus group. Cognitive testing (20) was conducted with 20 nurses to assess comprehension of the questions and categories of answers as

well as comprehension of the wording of questions with particular emphasis placed on the classification of the life- shortening end-of-life decisions. We asked the nurses to recall the most recent patient they had cared for whose treatment involved one or more life-shortening end-of-life decisions (Box 1). We selected only those cases in which the nurses reported that the patient had had life-ending drugs administered with the explicit intention of ending the patient's life. We further classified a case as "euthanasia" if the patient had made an explicit request for this act to be performed and as "the use of life-ending drugs without explicit request" if the patient had not.

Statistical analysis

Nurse and patient characteristics, and the nurse's involvement in decision-making and in administering life-ending drugs, are presented as frequencies and proportions. We used the Fisher exact test to compare differences in distributions between cases of euthanasia and cases involving the use of life-ending drugs without explicit request. We performed logistic regression analysis to study the relation between nurse and patient characteristics and the nurse's involvement in decision-making and in administering the drugs.

Results

Ten of the 1678 questionnaires were returned as undeliverable. Of the remaining 1668 questionnaires, 1265 were returned completed, for a response rate of 76%. Overall, 128 nurses reported that the last patient in their care for whom a life-shortening end-of-life decision was made received euthanasia; 120 nurses reported that the last patient in their care for whom a life-shortening end-of-life decision was made received life-ending drugs without his or her explicit request (Appendix 1). The characteristics of these 248 nurses are presented in **Table 1**. Among the nurses working in home care settings, more were involved in cases of euthanasia (25%) than in cases of assisted death without the patient's explicit request (10%). The opposite was observed among nurses working in care homes: 16% reported that their patient had received euthanasia and 27% that life-ending drugs had been used without the patient's explicit request. Most of the patients who received euthanasia were less than 80 years old (84% [102/122]), had cancer (78% [99/127]) and died in hospital (53% [68/128]). Most of the patients who received life- ending drugs without their explicit request were over 80 years old (42% [50/118]), had cancer (43% [52/120]) or cardiovascular disease (23% [28/120]) and died in hospital (64% [76/119]).

Table 1 - Characteristics of 248 nurses involved in cases of assisted death in Flanders, Belgium

	Type of assisted death; no. (%) of nurses	
Characteristic	**With patient's explicit request** ***n =128***	**Without patient's explicit request** ***n =120***
Sex, male	11 (9)	15 (12)
Age, yr	*n = 127*	*n = 117*
22-35	26 (20)	33 (28)
36-45	57 (45)	43 (37)
46-55	44 (35)	41 (35)
Educational level	*n = 126*	*n = 120*
Diploma/Associate degree	57 (45)	68 (57)
Baccalaureate degree	64 (51)	52 (43)
Master's degree	5 (4)	0
Work function	*n = 128*	*n = 120*
Bedside nurse	118 (92)	106 (88)
Head nurse	7 (5)	10 (8)
Other	3 (2)	4 (3)
Principal work setting	*n = 127*	*n = 119*
Hospital	75 (59)	75 (63)
Care home	20 (16)	32 (27)
Home care	32 (25)	12 (10)
Working in a specialist palliative care function	*n = 122* 20 (16)	*n = 116* 13 (11)

* p = 0.003 for comparison between study groups.

Of the nurses whose patient received euthanasia, 69% (84/122) reported that the patient had expressed his or her wishes about euthanasia to them. Of the

nurses whose patient received euthanasia, 64% (75/117) reported having been involved in the decision-making process, but with different experiences (Table 2). Of the nurses whose patient received life-ending drugs without his or her explicit request, 4% (5/119) reported that the patient had expressed his or her wishes about the decision to them. Involvement in the decision-making process was reported by 69% (81/118) of nurses (**Table 2**). In both groups, the physician and nurse deciding together occurred less often (24% in euthanasia group and 31% in group without explicit patient request) than did the exchanging information between physician and nurse about the patient's or relatives' wishes and the patient's condition (45% in euthanasia group and 51% in group without explicit patient request).

Table 2 - Nurses' involvement in decision-making in assisted deaths

	Type of assisted death; no. (%) of nurses	
Involvement	**With patient's explicit request** ***n =117***	**Without patient's explicit request** ***n =118***
Involved in decision-making†	75 (64)	81 (69)
Physician and nurse decided together	18 (24)	25 (31)
Nurse's personal opinion was asked or given	15 (20)	6 (7)
Nurse advocates for patient's or relatives' wishes	8 (11)	9 (11)
Physician and nurse exchanged information about patient's or relatives' wishes and about patient's condition	34 (45)	41 (51)
Not involved in decision-making	42 (36)	37 (31)
Only physician communicated decision after it was made	6 (14)	8 (22)
No communication with the physician about the decision	36 (86)	29 (78)

* The categories are exclusive; although nurses could have answered affirmatively in more than one category, the category with the most explicit level of involvement was used to classify their involvement.

In the cases of euthanasia, 40% of the nurses were involved in some way in the preparation of the life-ending drugs (**Table 3**). During the administration of the drugs, 34% of the nurses reported that they were present and 31% that they gave support to the patient, the relatives, the physician or colleague nurses. The drugs were administered by the nurse in 14 (12%) of the cases of euthanasia. The physician was not a co-administrator in 12 of the 14 cases, but the drug was always given on his or her orders. The nurse administered a neuromuscular relaxant in four cases, a barbiturate in one case and opioids in nine cases. In nine cases of euthanasia (64%), the physician was not present during the administration of the drugs.

In the cases involving the use of life-ending drugs without the patient's explicit request, 48% of the nurses reported that they had some part in the preparation of the drugs (**Table 3**). During the administration of the drugs, 56% reported that they were present and 51% that they gave support to the patient, the relatives, the physician or colleague nurses. The drugs were administered by the

nurse in 45 (45%) of the cases. The physician was not a co-administrator in 37 of these cases; however, the drug was given on his or her orders in almost all cases (42 of 43 in which this information was reported). The nurse administered a neuromuscular relaxant in 6 (13%) of the 45 cases, a barbiturate in 3 (7%) and opioids in 34 (76%). The physician was not present in 58% of the cases in which the nurse administered the life-ending drugs.

Table 3 - Nurses' involvement in administration of life-ending drugs in assisted deaths

Involvement	Type of assisted death; no. (%) of nurses		*p* value‡
	With patient's explicit request‡ n =128	**Without patient's explicit request† n =120**	
Before administration			
Had a role in preparing the life-ending drugs	47 (40)	53 (48)	0.23
Received the drugs from the pharmacist	24 (21)	19 (17)	0.61
Prepared and controlled the drugs	35 (30)	46 (42)	0.07
Set out the drugs/equipment for the physician	21 (18)	15 (14)	0.47
Passed the drugs/equipment to the physician	15 (13)	8 (7)	0.19
During administration			
Was present	43 (34)	65 (56)	0.001
Gave support§	39 (31)	59 (51)	0.002
To patient	29 (23)	15 (13)	0.05
To relatives	33 (26)	46 (40)	0.028
To physician	10 (8)	10 (9)	1.00
To colleague nurses	10 (8)	24 (21)	0.005
Administered the drugs	14 (12)	45 (45)	<0.001
With physician as co-administrator	2 (14)	8 (18)	1.00
By physician's orders	14 (100)	42 (98)	1.00
With physician's present			0.36
Yes, continuously	3 (21)	4 (10)	
Yes, intermittently	2 (14)	13 (32)	
No	9 (64)	23 (58)	
Type of drugs administered**			0.53
Neuromuscular relaxant	4 (29)	6 (13)	
Barbiturates	1 (7)	3 (7)	
Opioids	9 (64)	34 (76)	
Other	0	2 (4)	
No involvement	56 (48)	30 (28)	0.002

*Missing cases: 11 for "had a role in preparing the life-ending drugs," 1 for "was present during administration," 3 for "gave support," 12 for "administered the drugs" and 12 for "no involvement."
†Missing cases: 10 for "had a role in preparing the life-ending drugs," 4 for "was present during administration," 5 for "gave support," 20 for "administered the drugs," 2 for "by physician's orders" and 12 for "no involvement."
‡Calculated using Fisher exact test, for comparison between assisted death with and without explicit request from the patient.
§Multiple answers were possible.
**Drugs could have been neuromuscular relaxants, in any combination; barbiturates, alone or in combination with other drugs except neuromuscular relaxants; opioids, alone or in combination with other drugs except neuromuscular relaxants and barbiturates; benzodiazepines, alone or in combination with other drugs except neuromuscular relaxants, barbiturates and opioids; or other drugs, in any combination.

Compared with nurses in the euthanasia group, those involved in the cases without an explicit request from the patient more often were present during the administration of the life-ending drugs ($p = 0.001$), gave support ($p = 0.002$) and administered the life-ending drugs ($p < 0.001$) (**Table 3**).

Table 4 - Factors associated with nurses' involvement in decision-making and administration of life-ending drugs

Factor	Decision-making		Administration of drugs	
	p value	Adjusted OR (95%CI)*	*p* value	Adjusted OR (95%CI)*
Patient-related factor				
No explicit request	0.71	0.87 (0.40-11.65)	0.002	4.52 (1.75-11.65)
Female sex	0.53	0.80 (0.40-1.86)	0.16	0.56 (0.25-1.26)
Age > 80 years	0.32	1.50 (0.67-1.61)	0.001	5.57 (1.98-15.70)
Cause of death				
Malignant disease (ref)	-	1.00	-	1.00
Cardiovascular disease	0.86	1.11 (0.36-3.39)	0.67	0.76 (0.22-2.63)
Other	0.33	0.65 (0.27-1.55)	0.10	0.40 (0.13-1.21)
Nurse-related factor				
Age	0.001	0.92 (0.88-0.97)	0.54	0.98 (0.93-1.04)
Male sex	0.39	1.75 (0.48-6.36)	-	
Education level†	0.13	1.76 (0.85-3.64)	0.51	0.73 (0.28-1.88)
Home care setting as principal workplace	0.008	0.30 (0.13-0.74)	-	
Recent experience with end-of-life decision	0.27	1.48 (0.74-2.96)	0.05	2.55 (1.00-6.51)
Bedside nurse (v. other position)	0.30	0.48 (0.12-1.96)	0.75	0.78 (0.18-3.48)
Specialist palliative care function	0.11	2.50 (0.81-7.71)	0.51	1.47 (0.47-4.62)
Religious (v. not)	0.81	0.90 (0.38-2.15)	0.76	1.19 (0.40-3.57)
Religion considered important‡ (v. not)	0.66	0.85 (0.41-1.75)	0.78	0.88 (0.36-2.17)
Workplace x sex of nurse§				
Male nurse in hospital setting			< 0.001	40.07 (7.37-217.79)
Female nurse in hospital setting			0.002	5.92 (1.97-17.81)
Workplace setting other than hospital (ref)			-	1.00

Note: CI = confidence interval, OR = odds ratio, ref = reference group.
* Each odds ratio was adjusted for the other variables in the table.
† Diploma or associate degree (ref) v. baccalaureate or master's degree.
‡ In professional attitudes toward end-of-life decisions.
§ In this model, interaction occurred between the nurse's sex and work setting. Because there was an empty cell (no male nurses who administered life-ending drugs worked at a setting other than hospital), the two variables were transformed into a combined variable.

In the multivariable logistic regression analysis, factors significantly associated with a decreased involvement in decision-making were the nurse working in a home care setting (odds ratio [OR] 0.30, 95% confidence interval [CI] 0.13–0.74) and older age of the nurse (OR 0.92, 95% CI 0.88–0.97) (**Table 4**). Factors significantly associated with the nurse administering the life-ending drugs were the absence of an explicit request from the patient (OR 4.52, 95% CI 1.75–11.65), the patient being more than 80 years old (OR 5.57, 95% CI 1.98–15.70) and the nurse having had a recent experience with life-shortening end-of-life decisions (OR 2.55, 95% CI 1.00–6.51). Other factors were the sex and

principal workplace of the nurses: female nurses working in hospitals were nearly six times (OR 5.92, 95% CI 1.97–17.81) and male nurses working in hospitals were 40 times (OR 40.07, 95% CI 7.37–217.79) more likely than their male and female counterparts working in other settings to administer the life-ending drugs.

Discussion

In our study, more than half of the nurses surveyed in Flanders, Belgium, reported that they were involved in the physician's decision-making about the use of life-ending drugs. In most cases, the involvement was merely an exchange of information about the patient's or relatives' wishes and about the patient's condition. The nurse administered the life- ending drugs at the physician's request in many cases, most of which were cases without an explicit request from the patient.

The euthanasia law in Belgium states that the physician must discuss requests for euthanasia with the nurses involved (16). From the completed questionnaires we received, this did not always occur. In a survey of physicians in Belgium, only half of those who had had cases of euthanasia reported that they had involved nurses in their decision- making (9). In the study by Chambaere and colleagues, physicians reported having discussed the decision with the nurses in 54% of the cases of euthanasia or assisted suicide and in 40% of the cases of assisted death without the patient's explicit request (17). In our study, the involvement of nurses was restricted mainly to informing the physician about the patient's condition or the patient's and relatives' wishes. It appears that the physicians who did consult nurses recognized their value as providers of information, acknowledging their function as intermediaries between the physician and the patient or relatives, but that the shared decision- making between physician and nurse was less common. We observed a similar level of involvement in the cases of life-ending drugs given without the patient's explicit request. In such cases, the patient is usually no longer able to make a request because of exacerbation of symptoms or the progression of disease (21). From our findings, it seems that physicians were no more likely to involve nurses in their decision-making when the patient was unable to communicate his or her wishes than when they were able to.

In previous surveys, physicians reported that nurses sometimes administered drugs explicitly intended to hasten death (7,9,17,22). Nevertheless, uncertainty remained about the understanding by the nurses of the act that they performed. In our study, nurses did administer life-ending drugs with the recognition that the death of the patient was intended. In the cases of euthanasia, 12% of the nurses administered the drugs. In the United States, where no legal framework for euthanasia is provided, 16% of critical care nurses (10) and 5% of oncology nurses (11) reported engaging in euthanasia. Similar findings have been reported in other countries (14,15). In our study, administration of the life-ending drugs by the nurse occurred more frequently in the cases without an explicit request from the patient than in the cases of euthanasia. Previous studies have shown that nurses believe an explicit request from the patient is required when accepting an assisting role in dying (23-25). However, a recent study showed that nurses were not necessarily averse to the possibility of administering life-ending drugs without an explicit request from the patient, to the point of accepting an active role in it (18).

Different points about our findings deserve further attention. First, we wonder whether nurses overestimated the actual life-shortening effect of the drug administration, especially when opioids were used (26,27), and whether the physician had intended to end the patient's life when he or she ordered the nurse to administer the drugs. Nurses may have thought that they were ending the patient's life, when in fact the drugs were intended to relieve symptoms in an aggressive, but necessary manner. However, incidence studies worldwide have shown that physicians reported administering opioids with the explicit intention of ending the patient's life (4;28;29).

Second, we wonder why nurses more often administered the life-ending drugs in cases without an explicit patient request than in cases of euthanasia. Perhaps nurses took a more active role out of concern for frailer patients who could no longer communicate, or for very old patients because physicians are more reluctant to give assistance in dying when dealing with these patients.30 Further, in cases of euthanasia, communication between the physician and the patient is common. When the patient can no longer communicate, nurses are, by the nature of their work, more directly confronted with the patient's suffering and may therefore wish to take a more active role in life-ending acts (18). We also have to consider that the administration of life-ending drugs without the patient's explicit request may have included situations of terminal sedation or an increase in pain alleviation, in which the delegation by physicians to nurses to administer the drugs is considered common practice (21,31). Finally, although about half of the nurses' reports indicated that there was no explicit request from the patient, it should be stated that the physicians and nurses probably acted according to the patient's wishes (4,21).

Third, the nurses we surveyed who administered the life-ending drugs did not do so on their own initiative. Although the act was often performed without the physician being present, it was predominantly carried out on the physician's orders and under his or her responsibility. However, the administration of life-ending drugs by nurses, whether or not under the physician's responsibility, is not regulated under Belgium's euthanasia law and therefore not acceptable. In particular, when criteria for due care are not fulfilled, such as in cases where the patient has not made an explicit request, nurses, next to the physician, risk legal prosecution. Nurses may get caught in a vulnerable position between following a physician's orders and performing an illegal act. Further, physicians who perform euthanasia are required to report their case to a review committee after the act. In a study of all cases of euthanasia in Belgium, Smets and colleagues found that physicians did not always report their cases and that unreported cases often involved the use of opioids and the administration of them by nurses (32). It seems that the current law (which does not allow nurses to administer the life-ending drugs) and a control system do not prevent nurses from administering life-ending drugs. Therefore, professional guidelines are needed to help clarify their involvement in these practices.

Strengths and limitations

The large random sample of nurses, the high response rate, the comprehensive testing of the questionnaire with attention given to the interpretation of the life-shortening end-of-life decisions, the fact that recall was limited to the 12 months before the survey, and the endorsement of the study by professional nursing organizations contributed to the reliability of our results. However, the administration of drugs with the explicit intention of ending a patient's life is a sensitive, complex issue. Our study is possibly limited by selection bias, a reluctance of respondents to report illegal acts, the self-reported nature of the data and the lack of information from the attending physician or about the doses of drugs used. It is also unknown whether our findings are generalizable to practices elsewhere in the world, although the studied practices and legal prohibition of nurses' involvement in administering life-ending drugs exists worldwide (1-5;10;11;14;15;22;33;34).

Conclusion

By administering life-ending drugs at the physician's request in some cases of euthanasia, and even more so in cases without an explicit request from the patient, the nurses in our study operated beyond the legal margins of their profession. Future research should closely monitor and examine the involvement of nurses in these practices nationally and internationally to allow comparisons between countries with and without euthanasia legislation.

Acknowledgements

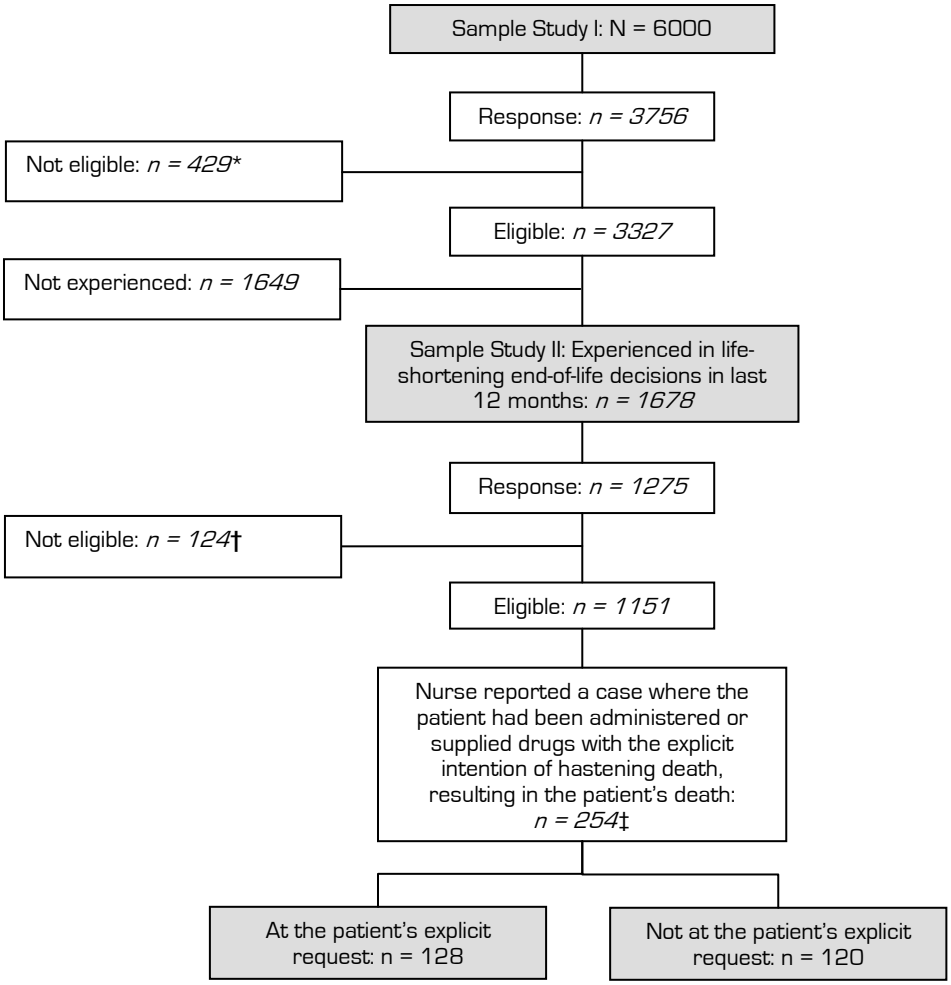
This study was supported by a grant from the Fund for Scientific Research Flanders, Belgium (G.0503.05N). The funding source had no role in design and conduct of the study; collection, management, analysis, and interpretation of the data; and preparation, review, or approval of the manuscript. The corresponding author had full access to all data in the study and takes responsibility for the integrity of the data and the accuracy of the data analysis. We thank Johan Vanoverloop and Koen Meeussen for their (statistical) advice; the Federal Ministry of Public Health, Safety of the Food Chain and Environment, Department Basic Health Care and Emergency Management for access to their federal government database; and the nurses who provided the study data.

References

(1) Kuhse H, Singer P, Baume P, Clark M, Rickard M. End-of-life decisions in Australian medical practice. Med J Aust 1997; 166(4):191-196.
(2) Meier DE, Emmons CA, Wallenstein S, Quill T, Morrison RS, Cassel CK. A national survey of physician-assisted suicide and euthanasia in the United States. N Engl J Med 1998; 338(17):1193-1201.
(3) van der Heide A, Deliens L, Faisst K, et al. End-of-life decision-making in six European countries: descriptive study. Lancet 2003; 362(9381):345-350.
(4) van der Heide A, Onwuteaka-Philipsen BD, Rurup ML, et al. End-of-life practices in the Netherlands under the Euthanasia Act. N Engl J Med 2007; 356(19):1957-1965.
(5) Seale C. End-of-life decisions in the UK involving medical practitioners. Palliat Med 2009; 23(3):198-204.
(6) Bosshard G, Broeckaert B, Clark D, Materstvedt LJ, Gordijn B, Muller-Busch HC. A role for doctors in assisted dying? An analysis of legal regulations and medical professional positions in six European countries. J Med Ethics 2008; 34(1):28-32.
(7) Bilsen JJ, Vander Stichele RH, Mortier F, Deliens L. Involvement of nurses in physician-assisted dying. J Adv Nurs 2004; 47(6):583-591.
(8) Seale C. Characteristics of end-of-life decisions: survey of UK medical practitioners. Palliat Med 2006; 20(7):653-659.
(9) Inghelbrecht E, Bilsen J, Mortier F, Deliens L. Factors related to the involvement of nurses in medical end-of-life decisions in Belgium: A death certificate study. Int J Nurs Stud 2008; 45(7):1022-1031.
(10) Asch DA. The role of critical care nurses in euthanasia and assisted suicide. N Engl J Med 1996; 334(21):1374-1379.
(11) Matzo ML, Emanual EJ. Oncology nurses' practices of assisted suicide and patient-requested euthanasia. Oncol Nurs Forum 1997; 24(10):1725-1732.
(12) De Bal N, Dierckx de Casterlé B, De Beer T, Gastmans C. Involvement of nurses in caring for patients requesting euthanasia in Flanders (Belgium): a qualitative study. Int J Nurs Stud 2006; 43(5):589-599.
(13) Ganzini L, Harvath TA, Jackson A, Goy ER, Miller LL, Delorit MA. Experiences of Oregon nurses and social workers with hospice patients who requested assistance with suicide. N Engl J Med 2002; 347(8):582-588.
(14) van Bruchem-van de Scheur G, van der Arend AJ, Abu-Saad HH, Spreeuwenberg C, van Wijmen FC, Ter Meulen RH. The role of nurses in euthanasia and physician-assisted suicide in The Netherlands. J Med Ethics 2008; 34(4):254-258.
(15) Kuhse H, Singer P. Voluntary euthanasia and the nurse: an Australian survey. Int J Nurs Stud 1993; 30(4):311-322.
(16) Law concerning euthanasia. Belgian official collection of the laws — 2002 June 22 [Dutch]. Available: www.health.fgov.be/euthanasie (accessed 2010 Apr. 29).
(17) Chambaere K, Bilsen J, Cohen J, et al. Physician-assisted deaths under the euthanasia law in Belgium: a population-based survey. *CMAJ* 2010. DOI:10.1503/cmaj.091876 [Epub ahead of print].
(18) Inghelbrecht E, Bilsen J, Mortier F, et al. Nurses' attitudes towards euthanasia and towards their role in euthanasia: a nationwide study in Flanders, Belgium. *Int J Nurs Stud* 2009;46:1209-18.
(19) Inghelbrecht E, Bilsen J, Mortier F, et al. Nurses' attitudes towards end-of-life decisions: a nationwide study in Flanders, Belgium. *Palliat Med* 2009;23:649-58.
(20) Collins D. Pretesting survey instruments: an overview of cognitive methods. *Qual Life Res* 2003;12:229-38.
(21) Rietjens JA, Bilsen J, Fischer S, et al. Using drugs to end life without an explicit request of the patient. *Death Stud* 2007;31:205-21.
(22) Muller MT, Pijnenborg L, Onwuteaka-Philipsen BD, et al. The role of the nurse in active euthanasia and physician-assisted suicide. *J Adv Nurs* 1997;26:424-30.
(23) Frileux S, Lelievre C, Munoz Sastre MT, et al. When is physician assisted suicide or euthanasia acceptable? *J Med Ethics* 2003;29:330-6.
(24) Guedj M, Gibert M, Maudet A, et al. The acceptability of ending a patient's life. *J Med Ethics* 2005;31:311-7.

(25) Teisseyre N, Mullet E, Sorum PC. Under what conditions is euthanasia acceptable to lay people and health professionals? *Soc Sci Med* 2005;60:357-68.
(26) Bendiane MK, Bouhnik AD, Favre R, et al. Morphine prescription in end-of-life care and euthanasia: French home nurses' opinions. *J Opioid Manag* 2007;3:21-6.
(27) Bilsen J, Norup M, Deliens L, et al. Drugs used to alleviate symptoms with life shortening as a possible side effect: end-of-life care in six European countries. *J Pain Symptom Manage* 2006;31:111-21.
(28) Rurup ML, Borgsteede SD, van der Heide A, et al. Trends in the use of opioids at the end of life and the expected effects on hastening death. *J Pain Symptom Manage* 2009;37:144-55.
(29) Vander Stichele RH, Bilsen JJ, Bernheim JL, et al. Drugs used for euthanasia in Flanders, Belgium. *Pharmacoepidemiol Drug Saf* 2004;13:89-95.
(30) De Gendt C, Bilsen J, Mortier F, et al. End-of-life decision-making and terminal sedation among very old patients. *Gerontology* 2008;55:99-105.
(31) Rietjens JA, Hauser J, van der Heide A, et al. Having a difficult time leaving: experiences and attitudes of nurses with palliative sedation. *Palliat Med* 2007;21: 643-9.
(32) Smets T, Bilsen J, Cohen J, et al. Legal euthanasia in Belgium. Characteristics of all reported euthanasia cases. *Med Care* 2010;48:187-92
(33) American Nurses Association. *American Nurses Association Position statement on active euthanasia*. Silver Spring (MD): The Association; 1994. Available: www.nursingworld.org/MainMenuCategories/HealthcareandPolicyIssues/ANAPositionStatements/EthicsandHumanRights.aspx (accessed 2009 Aug. 11).
(34) Scientific Union for Nursing and Midwifery. *Position on euthanasia*. Ghent (Belgium): The Union; 2002.

Appendix 1 - Flow chart of the two studies questioning nurses about their attitudes and role.



* In 23 cases we could not reach the respondent; in 191 cases the respondent was not a qualified nurse; in 208 cases the nurse had no experiences in patient care; in 2 cases the respondent no longer lived in Flanders; and in 5 cases the respondent was French-speaking.
† In 10 cases the nurse could not be reached anymore; in 114 cases the nurse reported on a patient for whom no end-of-life decision with a possible or certain life-shortening effect was made.
‡ In 6 cases there was a missing on the question whether the patient had posed an explicit request.

Appendix 2 - Extracts from the questionnaire used for the study.
This appendix presents a considerable part of the questionnaire in which we present the questions relevant for the role of nurses in the administration of life-ending drugs with the explicit intention to end the patient's life.

The involvement of nurses in end-of-life decisions

Introduction

As explained in the first questionnaire, end-of-life decisions is understood to mean the following three decisions:

Table 1. Three end-of-life decisions with a possible or certain life-shortening effect

Decision 1:	Withholding or withdrawing a potential life-prolonging treatment (including artificial food and/or fluid)
Decision 2:	The intensification of the medication for pain and/or symptom alleviation with a possible life-shortening effect
Decision 3:	The administering of life-ending drugs with the explicit intention of ending the patient's life

We ask you to recall the most recent patient you cared for whose treatment involved at least one of the three end-of-life decisions presented in table 1. In keeping this patient in mind, we ask you to answer all the following questions about this patient.

Information about this patient

1	What is this patient's gender?	☐ Male ☐ Female
2	What was the age of this patient at the time of death?	_____ years
3	What was the main diagnosis (max. one) of cause of death of this patient?	☐ Cancer: _____ ☐ Cardiovascular disease: _____ ☐ Respiratory disease: _____ ☐ Nervous system disease: _____ ☐ Dementia ☐ Old age / Complete deterioration ☐ Other: _____
4	Did this patient, during the last month before death, suffer from other disorders, illnesses or disabilities?	☐ Yes: _____ ☐ No ☐ Don't know
5	What was the place of death of this patient?	☐ At home or living with family ☐ Care home: home for elderly or nursing home ☐ Hospital (exc. Palliative care unit or nursing home unit in hospital) ☐ Palliative care unit (hospital) ☐ Somewhere else: _____
6	Did this patient, during the last month before death, stay somewhere other than at the place of death?	☐ Yes: _____ ☐ No ☐ Don't know
7	Which specialist palliative care initiatives were brought into action for this patient? *– More than one answer can be given –*	☐ None → **go to question 8** ☐ Palliative home care team ☐ Mobile palliative support team in care home ☐ Mobile palliative support team in hospital ☐ Palliative care unit (hospital)

☐ Reference persons for palliative care in a care home
☐ Reference persons for palliative care in home care
☐ Other: _____

Are you working in one of the above marked specialist palliative care initiatives? ☐ Yes ☐ No

End-of-life decisions taken with this patient

In the table (on page 1) we presented three possible life-shortening end-of-life decisions. In the following three questions we ask you whether the decision was taken for this patient.

8 Were potential life-prolonging treatments withheld or withdrawn (including artificial food or fluid) for this patient? ☐ Yes ☐ No

9 Was the medication for pain and/or symptom management intensified with a possible life-shortening effect for this patient? ☐ Yes ☐ No

10 Was the death of this patient the result of the administering of life-ending drugs with the explicit intention to end the patient's life? ☐ Yes → **go to the following question (10.1)** ☐ No → **go to question 11**

Please answer the following questions based on this last decision (question 10)

10.1 Was this decision taken at the explicit request of the patient? ☐ Yes ☐ No

10.2 Were you present during the administering of the drugs preceding the death of the patient followed? ☐ Yes ☐ No

10.3 Which persons did you support during this administering? *– More than one answer can be given –* ☐ Nobody ☐ Patient ☐ Relatives ☐ Physician ☐ Colleague-nurse(s) ☐ Other:_____

10.4 As far as you know, what drugs were administered to the patient preceding the death of the patient?

INSTRUCTION:
- If you marked the drugs in column **a**, go on to column **b**.
- If you marked 'You yourself' in column **b**, go on to column **c** and **d**.

	a – What drugs were given?	**b** – Who administered the drugs? *– More than one answer can be given –*						**FILL THIS PART IN IF YOU MARKED 'YOU YOURSELF' IN COLUMN b:** **c** – Did you administered the drugs on the physician's orders?		**d** – Was the physician present while you administered the drugs?		
		Physi-cian	You yourself	Other nurse	Pa-tient	Other	Don't know	Yes	No	Yes, conti-nuously	Yes, but not conti-nuously	No
Morphine or other opioids	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐
Benzodiazepines	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐
Barbiturates	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐
Neuromuscular relaxants	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐
Other: _____	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐
Don't know	☐											

10.5 Which one of following preparatory tasks preceding the administering of the drugs did you take on?
– More than one answer can be given –

- ☐ Preparing the surroundings/room of the patient
- ☐ Receiving the drugs from the pharmacist
- ☐ Preparation and control of the drugs
- ☐ Setting out the drugs/equipment for the physician
- ☐ Passing the drugs/equipment to the physician
- ☐ Other: _____
- ☐ None of the above

10.6 Was there communication (either written or oral) between you and the physician about this decision?

- ☐ Yes, once
- ☐ Yes, more than once
- ☐ No → **go to question 10.7**

Mark which of the following were applicable:

1	Physician communicated the decision after this decision was made	☐
2	Physician informed me of the wishes of the patient and/or relatives about this decision	☐
3	Physician asked me, before making this decision, for information about:	
	- the patient's condition	☐
	- the wishes of the patient and/or relatives	☐
4	Physician asked me, before making this decision, for my personal opinion about it	☐
5	Physician made the decision in consultation with me	☐
6	I informed the physician about the wishes of the patient and/or relatives	☐
7	I informed the physician about the patient's condition, before this decision was made	☐
8	I gave the physician my personal opinion about this decision	☐
9	I advocated for the wishes of the patient and/or relatives about this decision in discussion with the physician	☐

10.7 Was there communication between you and the patient and/or relatives about this decision?
– More than one answer can be given –

- ☐ Yes, with the patient → **mark the column under patient**
- ☐ Yes, with the relatives → **mark the column under relatives**
- ☐ No

Mark which of the following were applicable:

			patient	rela-tives
1	The patient/relatives communicated to me:	- what their wishes were about this decision	☐	☐
		- what their wishes were about this decision before telling the physician	☐	☐

Additional questions were asked, but were not covered in the paper.

...

Chapter 8

Continuous deep sedation until death in Belgium: a survey among nurses

Els Inghelbrecht, Johan Bilsen, Freddy Mortier, Luc Deliens

This paper has been submitted.

Abstract

Context Continuous deep sedation (CDS) is the subject of important debate but until now nurses have rarely been questioned about their involvement and perceptions.
Objectives To study the communication process between nurses and patients, relatives or physicians during the decision-making process, and how nurses perceive this end-of-life practice.
Methods In 2007, a two-phase large-scale study was conducted, involving a representative sample of nurses in Flanders, Belgium. The second part entailed a survey of 1679 nurses who reported an end-of-life decision within the previous year. Nurses were surveyed about their most recent case.
Results The response rate was 75.8%: 250 nurses reported a case of CDS (64.4% hospital, 18.4% care home, 17.1% home). Patients communicated their wishes regarding CDS to nurses in 21.7% of cases, relatives in 61.9%. Nurses were involved in physician decision-making in 55.1% of cases, mostly supplying information on relatives' opinions (36.4%) or patient's condition (43.7%). Physician and nurse made the decision jointly in 23.1% of cases. Nurses noted disagreements about CDS between people involved in 9.2% of cases and had objections to the CDS in 4.2%. Nurses perceived CDS as partially intended to hasten death in 48% and explicitly in 28% of cases, estimating possible or certain life-shortening in 95.6%.
Conclusion Nurses in different healthcare settings are often involved in communication about CDS. They see it mainly as a practice intended to hasten death with a life-shortening effect; due care criteria should be developed clarifying the distinctions between the responsibilities of nurses and physicians.

Introduction

At the end of a patient's life, medical decision-making often contributes to how and when the patient dies. Continuous deep sedation (CDS), defined as the administration of drugs to keep the patient in deep sedation or coma until death, can be applied as an option of last resort in cases of refractory symptoms that cannot be adequately treated otherwise (1-3). Different studies estimate CDS as occurring in between 2.5% and 16.5% of all deaths (4-8). In Flanders, Belgium, physicians reported using CDS in 14.5% of all deaths in 2007, which was substantially higher than in 2001 (8.2%) (8;9). A similar increase was found in the Netherlands (5;10) and the UK (6), suggesting that CDS is becoming more common in end of life care.

Most studies investigated the practice of CDS by focusing on the attitudes or experiences of physicians (4;7;11-13). In recent years, the ethical debate has also focused on the views of physicians on whether CDS should be considered as part of normal medical end-of-life practice, provided particular safeguards are met, or whether it is a covert form of euthanasia (3;14). The involvement and opinion of nurses has been studied less often, although they care for patients near death, usually get to know a patient's relatives, and work closely with the physician. During the process of CDS, which may last some time, nurses usually remain at the bedside, administer the drugs, look after the patient's comfort, monitor possible symptoms and answer the questions and concerns of relatives (15). It may be assumed that nurses work in close communication with the physician, and even make an important contribution to the physician's decision-making, yet the nature of their communication with the physician, patient and relatives, their actual involvement in the decision-making process preceding CDS, and their opinions about the practice of CDS have not yet been studied across all healthcare settings and on a large-scale level. Our study answers the following research questions:

1) Which nurses and which patients are involved in CDS?
2) To what extend do patients, relatives and physicians communicate with nurses about the wishes of patients and relatives on CDS?
3) Are nurses involved in the physician's decision-making preceding CDS, and, if so, in what ways?
4) How do nurses evaluate their cooperation with the physician?
5) What are the perceptions of nurses on the CDS practice:
    a. do they estimate CDS to have been performed with the intention of hastening death and to have had a life-shortening effect?
    b. do they perceive disagreement between those involved about the CDS?
    c. Did they have objections to the CDS and have they refused to perform certain tasks assigned by the physician?

Methods

Respondent characteristics

This study was part of a two-phased large-scale study investigating nurses' attitudes towards end-of-life decisions with a possible or certain life-shortening effect and their involvement in such decisions in Flanders, the Dutch speaking part of Belgium, which contains about 60% of the country's inhabitants. In the first phase a random sample of 6000 nurses, drawn from a federal government database, were sent a questionnaire about attitudes towards this topic (**Figure 1**). More information about characteristics of the study population and findings related to nurses' attitudes is reported elsewhere (16;17). The second part of the study entailed 1678 nurses who reported in the first questionnaire that they had experience with caring for patients for whom end-of-life decisions with a possible or certain life-shortening effect, including the administering of medication to bring the patient into a coma until death had been made in the last 12 months. The data collection of this part of the study was done between November 2007 and February 2008. Three follow-ups were provided in cases of non-response. We ensured confidentiality by processing all data anonymously. The Ethics Committee of the University Hospital of the Vrije Universiteit Brussel granted ethical approval.

Questionnaire

We presented at the beginning of the questionnaire different types of decisions that could be taken at the end of a patient's life: withholding or withdrawing a potential life-prolonging treatment, intensification of pain and/or symptom alleviation with a possible life-shortening effect, using medication to bring the patient into a coma until death, and administering or supplying drugs in lethal doses explicitly intended to hasten death. We asked the nurses to recall the last patient in their care whose treatment involved one or more of those decisions. For this study, we selected those reported cases in which the nurse declared that medication was used to put the patient into a coma until death ie continuous deep sedation (CDS). The first part of the questionnaire surveyed patient characteristics, such as age at death, sex and main diagnosis. For patients who received CDS, the nurses had to fill in questions about: (1) communication of wishes about CDS between nurses and patients/relatives; (2) communication between physician and nurse about CDS, and if applicable, content of the communication; (3) the nurse's personal judgment about the intention to hasten death and the life-shortening effect of the CDS; (4) perceived disagreements between those involved about the CDS, and if applicable, between whom; (5) whether the nurse had objections to the CDS and refused to perform certain tasks requested by the physician concerning it; and (6) how positively they evaluated their experience of cooperation with the physician on the CDS, measured on a five-point Likert scale (-2= totally not to +2= totally yes). In the questionnaire in the first study about nurses' attitudes – the two questionnaires were linked to each other after the data collection – we asked the nurses for some personal and work-related characteristics.

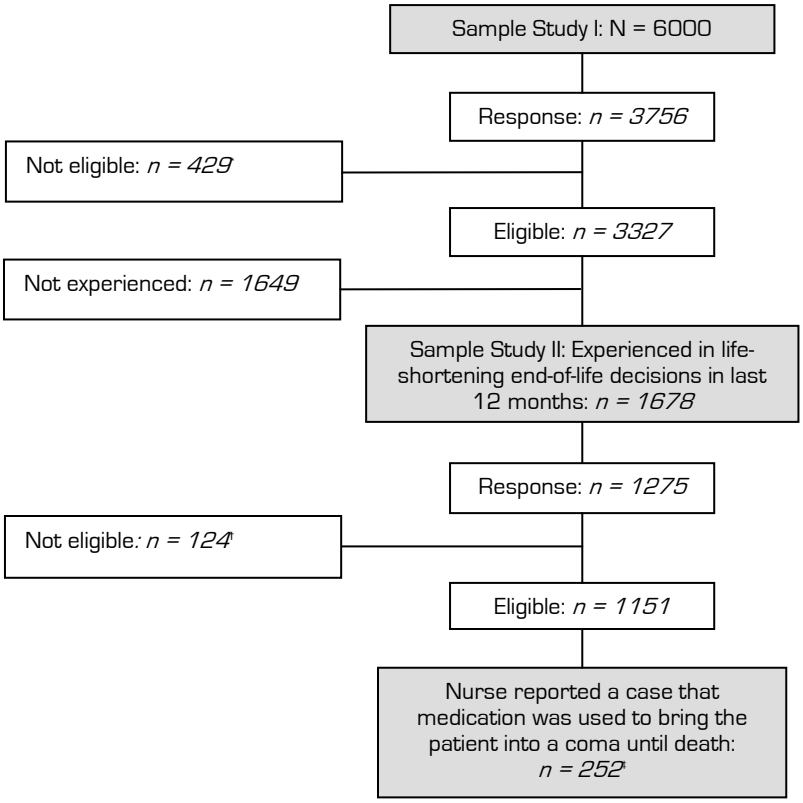


Figure 1. Flow chart of the studies questioning nurses about their attitudes and role
* In 23 cases we could not reach the respondent; in 191 cases the respondent was not a qualified nurse; in 208 cases the nurse had no experiences in patient care; in 2 cases the respondent no longer lived in Flanders; and in 5 cases the respondent was French-speaking.
† In 10 cases the nurse could not be reached anymore; in 114 cases the nurse reported on a patient for whom no end-of-life decision was made.
‡ Two cases were further excluded from the analyses as there were too many missing values.

The validity of the questionnaire was enhanced through expert review by an ethicist, a health scientist, a medical sociologist and two nurses, all experienced in end-of-life research, and through an in-depth discussion in a focus group (which included a palliative home care nurse, a psychologist specializing in palliative care, and two nurses working in policymaking on end-of-life decisions). Cognitive testing (18) was conducted with 20 nurses to assess comprehension of the questions and answer categories and question wording. Particular emphasis was placed on the interpretation of the different decisions that could be taken at the end of the patient's life.

Statistical analysis
Nurses' communication about and perception of CDS were analyzed in terms of frequencies and percentages, and presented for the three most common settings where nurses work (i.e. hospitals, care homes, and home care).

Differences in these aspects between the settings were tested using Fisher's exact test. Further, we used logistic regression analysis for testing the association between the nurse's involvement in the physician's decision-making and their positive evaluation of the cooperation with the physician on the CDS, and corrected for the setting and for patient and nurse characteristics. Adjusted odds ratios and 95% confidence intervals were calculated. All data were analyzed using SPSS17.0 (SPSS Inc, Chicago, IL).

Results

Of 1678 questionnaires, 10 were returned as undeliverable and 1265 were returned completed (response rate, 76%) of which 1151 included a report of a patient who received one or more end-of-life decisions (**Figure 1**). The nurses reported 252 CDS cases (21.9%) of which we excluded two, as there were too many missing values. These cases of CDS were reported by 161 nurses working in a hospital (64.4%), by 46 home care nurses (18.4%) and by 43 working in a care home (17.1%). Most were female (87.2%) and worked as bedside nurses (91.2%). Seventeen per cent worked in a palliative care function (**Table 1**).

Table 1 - Characteristics of nurses involved in caring for patients who received continuous deep sedation (N=250)*

	no.	(%)
Setting		
Hospital	161	(64.4)
Care home	43	(17.2)
Home care	46	(18.4)
Female gender	218	(87.2)
Age, y†	41.9	(8.0)
Educational level		
Diploma/Associate degree	105	(42.0)
Baccalaureate degree	142	(56.8)
Master's degree	3	(1.2)
Work function		
Bedside nurse	227	(91.2)
Head nurse	16	(6.4)
Other	6	(2.4)
Working in a palliative care function‡	40	(16.9)

* Missing cases for nurses' age, n=4; for work function, n=1; and for working in a palliative care function, n=9.
† mean and (standard deviation) are presented.
‡ Working in a palliative care function in Belgium means that nurses occupy a position in their work setting which implies an extra knowledge about palliative care, going from being a palliative referent nurse in home care or care home to working in a palliative care unit in a hospital.

Of the involved patients, 69.9% were 65 years or older and 54.0% had cancer (**Table 2**). In care homes, CDS was used more often among female patients, older patients, those dying from causes other than cancer and cardiovascular diseases, and patients with dementia. At home, CDS was used most often among patients who died from cancer and those who had a palliative care service or nurse involved.

Table 2. Characteristics of patients who received continuous deep sedation, by setting (N=250)*

	no. (%) of patients								
	All settings ***N=250***		**Hospital** ***n=161***		**Care home** ***n=43***		**Home care** ***n=46***		*p* value†
Female gender	131	(52.4)	77	(47.8)	31	(72.1)	23	(50.0)	.017
Age									< .001
≤64y	73	(30.2)	61	(39.6)	2	(4.7)	10	(22.2)	
65y to 79y	95	(39.3)	63	(40.9)	7	(16.3)	25	(55.6)	
≥80y	74	(30.6)	30	(19.5)	34	(79.1)	30	(22.2)	
Cause of death									< .001
Cancer	135	(54.0)	85	(52.8)	8	(18.6)	42	(91.3)	
Cardiovascular diseases	46	(18.4)	35	(21.7)	9	(20.9)	2	(4.3)	
Other	69	(30.6)	41	(25.5)	26	(60.5)	2	(4.3)	
Diagnosis of dementia	26	(10.4)	10	(6.2)	14	(32.6)	2	(4.3)	< .001
Multidisciplinary palliative care service involved‡	155	(64.6)	81	(52.6)	32	(78.0)	42	(93.3)	< .001

* Missing cases for patient's age, n=8; and for specialist palliative care involved, n=10.
† Differences between the three settings were tested using Fisher's Exact Test.
‡ In Belgium, these services can include a home care team, a care home team, a mobile hospital team, an inpatient palliative care unit, or palliative day care. Further, a palliative referent nurse in home care or care home can also be involved.

Nurses' communication about wishes on CDS

In 21.7% of cases, nurses reported that the patient had told them his/her wishes about CDS, in 9.8% of cases before telling the physician (**Table 3**). In 16% of cases, nurses asked the patient about his/her wishes. Relatives told nurses their wishes about CDS in 61.9% of cases, in 29.5% before telling the physician. Nurses stimulated relatives to talk about their wishes to the physician in 37.7% of cases. Higher communication rates between the nurse and the patient and relatives were observed in home care.

In 51.0% of cases, the nurse communicated with the physician about the wishes of the patient and/or relatives concerning CDS. The physician more often informed the nurse about the nature of those wishes (33.2%) than the nurse informed the physician (15.8%). No large differences were found between the different settings.

Nurses' involvement in the physician's decision-making

In 55.1% of cases, nurses reported being involved in the physician's decision-making (**Table 4)**. The physician most frequently asked the nurse for information about the patient's condition (43.7%) and the relatives' opinions about CDS (36.4%) before making the CDS decision. At home, the physician asked the nurse less often for information about the patient's condition than in the other settings. The physician and nurse decided together in 23.1% of cases.

Table 3. Nurses' communication with patient, relatives and physician about wishes on continuous deep sedation, by setting*

	no. (%) of nurses			
	All settings ***N=250***	**Hospital** ***n=161***	**Care home** ***n=43***	**Home care** ***n=46***
Nurse communicated with patient about wishes concerning CDS†	60 (24.6)	38 (24.1)	7 (17.1)	15 (33.3)
Patient told their wishes to nurse	53 (21.7)	33 (20.9)	6 (14.6)	14 (31.1)
before telling to physician	24 (9.8)	16 (10.1)	5 (12.2)	3 (6.7)
Nurse asked patient for their wishes	39 (16.0)	21 (13.3)	5 (12.2)	**13** **(28.9)**
Nurse stimulated patient to talk to physician about their wishes	38 (15.6)	21 (13.3)	5 (12.2)	**12** **(26.7)**
Nurse communicated with relatives about wishes concerning CDS†	163 (66.8)	101 (63.9)	27 (65.9)	35 (77.8)
Relatives told their wishes to nurse	151 (61.9)	95 (60.1)	23 (56.1)	33 (73.3)
before telling to physician	72 (29.5)	44 (27.8)	12 (29.3)	16 (35.6)
Nurse asked relatives for their wishes	88 (36.1)	**45** **(28.5)**	19 (46.3)	**24** **(53.3)**
Nurse stimulated relatives to talk to physician about their wishes	92 (37.7)	57 (36.1)	14 (34.1)	21 (46.7)
Nurse communicated with physician about P/R's wishes concerning CDS†	126 (51.0)	84 (52.5)	20 (46.5)	22 (50.0)
Physician informed nurse about P/R's wishes	82 (33.2)	57 (35.6)	12 (27.9)	13 (29.5)
Nurse informed physician about P/R's wishes	39 (15.8)	26 (16.3)	7 (16.3)	6 (13.6)
In discussion with physician, nurse asserted P/R's wishes	57 (23.1)	32 (20.0)	11 (25.6)	14 (31.8)

Abbreviations: CDS=continuous deep sedation; P/R=Patient/Relatives. Bold and underlined indicates that differences were found between the given setting and the other settings, P<0.05, using Fisher's exact test.
* Missing cases for nurse communicated with patient about wishes, n=6; for nurse communicated with relatives about wishes, n=6; and for nurse communicated with physician about wishes, n=3.
† Multiple answers possible.

Of all nurses caring for a patient who received CDS, 72.6% evaluated cooperation with the physician on the CDS as positive, 12% as neutral and 14.8% as negative. Nurses in home care evaluated cooperation with the physician less often as positive (59.0%) than hospital nurses (76.0%) and care home nurses (73.2%). The multivariable analyses correcting for differences in setting and patient and nurse characteristics revealed that nurses more often evaluated the cooperation as positive when they were involved in the physician's decision-making than when they were not (odds ratio 3.53, 95% Confidence Interval 1.72 to 7.26). As for the content of decision-making, the highest chances of evaluating the cooperation as positive were observed in cases where the physician asked the nurse for his/her personal opinion about the CDS (6.06, 1.25 to 29.32) and when the nurse and physician had made the decision together (3.57, 1.26 to 10.12).

Table 4. Nurses' involvement in the physician's decision-making and nurses' evaluation of the cooperation with physician on continuous deep sedation*

	no. (%) of nurses			
	All settings ***N=250***	**Hospital** ***n=161***	**Care home** ***n=43***	**Home care** ***n=46***
Nurse involved in physician's decision-making concerning CDS†	136 (55.1)	89 (55.6)	27 (62.8)	20 (45.5)
Physician asked nurse for information about patient's condition before making the CDS decision	108 (43.7)	73 (45.6)	22 (51.2)	**13 (29.5)**
Physician asked nurse for information about relatives' opinions before making the CDS decision	90 (36.4)	57 (35.6)	21 (48.8)	12 (27.3)
Physician and nurse decided together	57 (23.1)	35 (21.9)	13 (30.2)	9 (20.5)
Physician asked for nurse's opinion about the CDS	34 (13.8)	22 (13.8)	5 (11.6)	7 (15.9)
Nurse evaluation of the cooperation with the physician on CDS				
(Very) positive	167 (72.6)	114 (76.0)	30 (73.2)	**23 (59.0)**
Neutral	29 (12.0)	18 (12.0)	4 (9.8)	**7 (17.0)**
(Totally) not positive	34 (14.8)	18 (12.0)	7 (17.1)	**9 (23.1)**

Abbreviations: CDS=continuous deep sedation. Bold and underlined indicates that differences were found between the given setting and the other settings, P<0.05, using Fisher's exact test.
* Missing cases for nurse being involved in the physician's decision-making, n=3; and for evaluation of the cooperation with the physician, n=20.
† Multiple answers possible.

Nurses' evaluation of CDS

In 48.4% of cases, nurses reported that the CDS decision was made partly with the intention of hastening death and in 28.4% with the explicit intention of doing so (**Table 5**). Nurses reported that CDS had a certain life-shortening effect in 44.4% of cases and no life-shortening effect in 4.4%. Care home nurses more frequently judged that it had had a possible life-shortening effect (69.8%) than did home care (48.9%) and hospital nurses (46.9%). Further, 22 nurses (9.2%) indicated that there were disagreements between different parties about the CDS, mostly involving the relatives (11 cases). There were also disagreements among members of the healthcare team in 11 cases (data not shown). Finally, ten nurses (4.2%) had objections to the CDS for the patient and 8 nurses (3.5%) had refused to perform certain tasks related to it. In home care, nurses more often refused to perform certain tasks (10.3%) than in hospitals (1.3%).

Table 5. Nurses' evaluation of the cases of continuous deep sedation, by setting*

	no. (%) of nurses			
	All settings ***N=250***	**Hospital** ***n=161***	**Care home** ***n=43***	**Home care** ***n=46***
Intention to hasten death				
Without the intention	58 (23.2)	34 (21.1)	11 (25.6)	13 (28.3)
Partly with the intention	121 (48.4)	77 (47.8)	23 (53.5)	21 (45.7)
With the explicit intention	71 (28.4)	50 (31.1)	9 (20.9)	12 (26.1)
Estimated life-shortening effect				
No life-shortening	11 (4.4)	8 (5.0)	**0 (0)**	3 (6.7)
Possible life-shortening	127 (51.2)	75 (46.9)	**30 (69.8)**	22 (48.9)
Certain life-shortening	110 (44.4)	77 (48.1)	**13 (30.2)**	20 (44.4)
Nurse noted disagreements about the CDS between persons involved	22 (9.2)	14 (9.0)	4 (9.8)	4 (9.1)
Nurse had objections to the CDS	10 (4.2)	6 (3.9)	1 (2.4)	3 (7.3)
Nurse had refused to perform certain tasks assigned by the physician concerning CDS	8 (3.5)	**2 (1.3)**	2 (4.9)	**4 (10.3)**

Abbreviations: CDS=continuous deep sedation. Bold and underlined indicates that differences were found between the given setting and the other settings, P<0.05, using Fisher's exact test.
* Missing cases for estimated life-shortening effect, n=2; for disagreements, n=10; for objections, n=14; for refusing certain tasks, n=21.

Discussion

Nurses are confronted with continuous deep sedation (CDS) in many different healthcare settings. Their mediation role in CDS is important: relatives tell nurses their wishes concerning CDS in 62% of cases. Half of the nurses were involved in the physician's decision-making. About 77% thought that the CDS was partly or explicitly intended to hasten death, and only 4% believed that it had actually had no life-shortening effect.

This is, to our knowledge, the first study that questions nurses on a large-scale level about CDS, an end-of-life practice that is widely used and debated. The initial large random sample of nurses and the high response rate ensure generalisability to nurses who are involved in CDS. The study's limitations include that nurses may have had difficulties recalling all the details about the patient and the communication process of the CDS. However, recall bias was probably limited as the case was limited to the last 12 months. Our study may also have been subject to selection bias because nurses will be more likely to remember a case in which their involvement was greater or where the CDS had been more controversial in terms of the intention to hasten death. Next, we lack details about the wishes of the patient and relatives eg we do not know whether the views they had expressed were in favor of carrying out CDS, the principle of CDS etc. Another limitation included that we asked the nurses to recall a patient whose treatment involved an end-of-life decision with a possible or certain life-shortening effect, including the administering of medication to bring the patient into a coma until death. It is possible that nurses rather selected a case of continuous deep sedation which might have had potential or certain life-shortening effect than a case without any life-shortening effect. Still, the exact wording that we used for categorizing continuous deep sedation did not included any life-shortening effect or intent. Finally, it is unknown whether our findings are generalisable to other countries because there is a relatively high occurrence of CDS in Belgium (8).

Nurses across different healthcare settings are involved in CDS. Generally, our study shows that researching the practice of CDS should not be restricted to palliative care or intensive care settings, as most studies have been (19-23), because these groups of nurses are a minority of those involved in CDS. Additionally, from comparisons with other studies exploring the practice of CDS by questioning physicians (7;9;10;24), we found no noticeable differences in patient characteristics between the patients involved in those studies and those in our study. Hence, our results may be generalized to all patients receiving CDS.

Our study shows that relatives express their wishes on CDS to the nurse more often than the patient does. This higher frequency of involvement of relatives may be explained by the fact that the patients themselves were in many cases no longer able to communicate, something confirmed by other studies (7;19;20;25), which might indicate that communication about CDS with the patient has begun too late. Another explanation is that CDS is first proposed by

the physician and even sometimes by the relatives (19;26) which is in clear contrast with other much-debated end-of-life practices such as euthanasia, which in Belgium and the Netherlands is unequivocally patient-driven (27). The fact that relatives regularly express their wishes about CDS to nurses (in 62% of cases) and even, in 30% of cases, before informing the physician, indicates that relatives perceive nurses as being more accessible or approachable than the physician. Our results also show that nurses stimulate relatives to talk about their wishes to the physician, confirming other studies on end-of-life practices which show that nurses often fulfill the role as intermediaries between patient, relatives and physician, and appear to have some advocatory role with the physician on behalf of the patient and/or the relatives (23;28).

Only half of nurses are involved in the physician's decision-making about CDS, a finding which is in line with another study performed among physicians (7). In palliative care units, physicians nearly always discussed the decision in team or personally with nurses (29;30). Furthermore, the involvement of nurses in the decision-making process implies more that the physician asks them about the patient's condition and the relatives' opinions rather than seeking their opinion or making joint decisions. However, a considerable number of nurses are involved in co-decision-making in CDS. On the other hand, our study shows that nurses evaluate their cooperation with the physician positively most often when their opinion about the CDS has been requested.

As far as differences between the healthcare settings are concerned, there is markedly more communication about wishes of patients and relatives in home care than in hospitals and care homes. The higher incidence of communication is probably explained by the fact that nurses who care for patients at home do so in the patient's and relatives' own surroundings, which can induce a more informal level of contact in which end-of-life wishes can more easily be discussed. This is, however, not translated into a greater level of nurse-involvement in the physician's decision-making. Apparently, general practitioners make no more use of a nurse's knowledge of the patient's and relatives' wishes than do physicians in hospitals and care homes. This could explain the lower evaluation of cooperation with the physician among home care nurses than in the other settings, and the higher rates of refusal to perform certain tasks involving CDS.
More than half of nurses thought the CDS to be partially or explicitly intended to hasten death. The vast majority of nurses also believe that the CDS shortened the patient's life, though multiple empirical studies have suggested that such sedation has no proven life-shortening effect (20;22;26;30;31). It could be that nurses overestimate the actual life-shortening effect of CDS as they regularly do in cases of the use of opioids, and also do more often than physicians (32;33). However, it could equally be that perhaps physicians underestimate the actual life-shortening effect when using CDS. This raises the question of whether nurses consider CDS as morally equivalent to and ethically indistinguishable from euthanasia (14). In a US study performed with palliative and intensive care nurses, some thought that CDS at times approximated the practice of euthanasia (23). Lo & Rubenfeld assumed that nurses think that they are

causing death when terminally sedating a patient, even if they understand intellectually the rationale behind the sedation (1). In any case, it seems that nurses consider the practice of CDS as a controversial one through which they may experience ethical dilemmas leading to a high emotional burden (34). Our study additionally shows that some nurses had objections to CDS, some refused to perform certain tasks assigned by the physician and some reported disagreements about CDS between the people involved (patient, relatives, physician, nurses). All these findings strengthen the hypothesis that CDS is experienced as an ethically problematic practice.

Our study suggests that CDS should be covered extensively in basic nursing education and training. It is important for clinical practice that the nurse who provides the care for a patient should be involved in decision-making about it, not only in order that any decision-making should be shared but also that the goals of care and the objectives and purpose of the CDS become clear to all healthcare professionals involved. Guidelines should recommend clear discussions between the physician and the nurses in which the physician states the purpose and estimated effect of the decision (35;36). Finally, the development of due care criteria is recommended, including stipulations for conscientious objection and procedures for consultation among healthcare teams, and a clear distinction made between the responsibilities of nurses and physicians which may elicit any ethical/moral concerns the nurses may have about the use of CDS.

In this study, we sought information from the nurse and not from the physician or the relatives; comparing their views on the involvement of nurses, the intention to hasten death and the life-shortening effect would give more insight into the practice of CDS. Research should include a longitudinal timeframe to investigate how the different people involved (patient, relatives, physician and nurses) experience CDS. This should be done nationally and internationally to allow comparisons and increase understanding of this complex end-of-life practice. Whether or not this practice and the involvement of nurses in it would benefit the provision of high quality end of life care for the patient and his relatives is an important unanswered question to be studied.

Acknowledgements

This study was supported by a grant from the Fund for Scientific Research Flanders, Belgium (G.0503.05N). The funding source had no role in design and conduct of the study; collection, management, analysis, and interpretation of the data; and preparation, review, or approval of the manuscript. The corresponding author had full access to all data in the study and takes responsibility for the integrity of the data and the accuracy of the data analysis. The authors thank the nurses who provided the study data; J. Vanoverloop for his statistical advise; K. Meeussen for his recommendations about the text; J. Ruthven for translation advice; and the Federal Ministry of Public Health, Safety of the Food Chain and Environment, Department Basic Health Care and Emergency Management for access to their federal government database.

References

(1) Lo B, Rubenfeld G. Palliative sedation in dying patients: "we turn to it when everything else hasn't worked". JAMA 2005; 294(14):1810-1816.
(2) Quill TE, Lee BC, Nunn S. Palliative treatments of last resort: choosing the least harmful alternative. University of Pennsylvania Center for Bioethics Assisted Suicide Consensus Panel. Ann Intern Med 2000; 132(6):488-493.
(3) Quill TE, Lo B, Brock DW. Palliative options of last resort: a comparison of voluntarily stopping eating and drinking, terminal sedation, physician-assisted suicide, and voluntary active euthanasia. JAMA 1997; 278(23):2099-2104.
(4) Miccinesi G, Rietjens JA, Deliens L, et al. Continuous deep sedation: physicians' experiences in six European countries. J Pain Symptom Manage 2006; 31(2):122-129.
(5) van der Heide A, Onwuteaka-Philipsen BD, Rurup ML, et al. End-of-life practices in the Netherlands under the Euthanasia Act. N Engl J Med 2007; 356(19):1957-1965.
(6) Seale C. End-of-life decisions in the UK involving medical practitioners. Palliat Med 2009; 23(3):198-204.
(7) Rietjens JA, van der Heide A, Vrakking AM, Onwuteaka-Philipsen BD, van der Maas PJ, van der Wal G. Physician reports of terminal sedation without hydration or nutrition for patients nearing death in the Netherlands. Ann Intern Med 2004; 141(3):178-185.
(8) Bilsen J, Cohen J, Chambaere K, et al. Medical end-of-life practices under the euthanasia law in Belgium. A nationwide post-mortem survey. N Engl J Med 2009; 361(11):1119-1121.
(9) Chambaere K, Bilsen J, Cohen J, et al. Continuous deep sedation until death in Belgium: a nationwide survey. Arch Intern Med 2010;Forthcoming.
(10) Rietjens J, van Delden J, Onwuteaka-Philipsen B, Buiting H, van der Maas P, van der Heide A. Continuous deep sedation for patients nearing death in the Netherlands: descriptive study. BMJ 2008; 336(7648):810-813.
(11) Morita T, Akechi T, Sugawara Y, Chihara S, Uchitomi Y. Practices and attitudes of Japanese oncologists and palliative care physicians concerning terminal sedation: a nationwide survey. J Clin Oncol 2002; 20(3):758-764.
(12) Rietjens JA, van der Heide A, Onwuteaka-Philipsen BD, van der Maas PJ, van der Wal G. A comparison of attitudes towards end-of-life decisions: Survey among the Dutch general public and physicians. Soc Sci Med 2005; 61(8):1723-1732.
(13) Hasselaar JG, Reuzel RP, van den Muijsenbergh ME, et al. Dealing with delicate issues in continuous deep sedation. Varying practices among Dutch medical specialists, general practitioners, and nursing home physicians. Arch Intern Med 2008; 168(5):537-543.
(14) Billings JA, Block SD. Slow euthanasia. J Palliat Care 1996; 12(4):21-30.
(15) Engstrom J, Bruno E, Holm B, Hellzen O. Palliative sedation at end of life - a systematic literature review. Eur J Oncol Nurs 2007; 11(1):26-35.
(16) Inghelbrecht E, Bilsen J, Mortier F, Deliens L. Attitudes of nurses towards euthanasia and towards their role in euthanasia: a nationwide study in Flanders, Belgium. Int J Nurs Stud 2009; 46(9):1209-1218.
(17) Inghelbrecht E, Bilsen J, Mortier F, Deliens L. Nurses' attitudes towards end-of-life decisions in medical practice: a nationwide study in Flanders, Belgium. Palliat Med 2009; 23(7):649-658.
(18) Collins D. Pretesting survey instruments: An overview of cognitive methods. Quality of Life Research 2003; 12(3):229-238.
(19) Morita T, Chinone Y, Ikenaga M, et al. Ethical validity of palliative sedation therapy: a multicenter, prospective, observational study conducted on specialized palliative care units in Japan. J Pain Symptom Manage 2005; 30(4):308-319.
(20) Chiu TY, Hu WY, Lue BH, Cheng SY, Chen CY. Sedation for refractory symptoms of terminal cancer patients in Taiwan. J Pain Symptom Manage 2001; 21(6):467-472.
(21) Muller-Busch HC, Andres I, Jehser T. Sedation in palliative care - a critical analysis of 7 years experience. BMC Palliat Care 2003; 2(1):2.
(22) Sykes N, Thorns A. Sedative use in the last week of life and the implications for end-of-life decision making. Arch Intern Med 2003; 163(3):341-344.
(23) Rietjens JA, Hauser J, van der Heide A, Emanuel L. Having a difficult time leaving: experiences and attitudes of nurses with palliative sedation. Palliat Med 2007; 21(7):643-649.

(24) Van den Block L, Deschepper R, Bilsen J, Bossuyt N, Van Casteren V, Deliens L. Euthanasia and other end of life decisions and care provided in final three months of life: nationwide retrospective study in Belgium. BMJ 2009; 339:b2772.
(25) Morita T, Ikenaga M, Adachi I, et al. Family experience with palliative sedation therapy for terminally ill cancer patients. J Pain Symptom Manage 2004; 28(6):557-565.
(26) Mercadante S, Intravaia G, Villari P, Ferrera P, David F, Casuccio A. Controlled sedation for refractory symptoms in dying patients. J Pain Symptom Manage 2009; 37(5):771-779.
(27) Rietjens JA, van Delden JJ, van der Heide A, et al. Terminal sedation and euthanasia: a comparison of clinical practices. Arch Intern Med 2006; 166(7):749-753.
(28) Inghelbrecht E, Bilsen J, Mortier F, Deliens L. The role of nurses in physician-assisted dying: nationwide retrospective study in Belgium. CMAJ 2010;Forthcoming.
(29) Morita T. Palliative sedation to relieve psycho-existential suffering of terminally ill cancer patients. J Pain Symptom Manage 2004; 28(5):445-450.
(30) Rietjens JA, van Zuylen L, van Veluw H, van der Wijk L, van der Heide A, van der Rijt CC. Palliative sedation in a specialized unit for acute palliative care in a cancer hospital: comparing patients dying with and without palliative sedation. J Pain Symptom Manage 2008; 36(3):228-234.
(31) Morita T, Tsunoda J, Inoue S, Chihara S. Effects of high dose opioids and sedatives on survival in terminally ill cancer patients. J Pain Symptom Manage 2001; 21(4):282-289.
(32) Bendiane MK, Bouhnik AD, Favre R, et al. Morphine prescription in end-of-life care and euthanasia: French home nurses' opinions. J Opioid Manag 2007; 3(1):21-26.
(33) Peretti-Watel P, Bendiane MK, Moatti JP. Attitudes toward palliative care, conceptions of euthanasia and opinions about its legalization among French physicians. Soc Sci Med 2005; 60(8):1781-1793.
(34) Morita T, Miyashita M, Kimura R, Adachi I, Shima Y. Emotional burden of nurses in palliative sedation therapy. Palliat Med 2004; 18(6):550-557.
(35) Verkerk M, van Wijlick E, Legemaate J, de Graeff A. A national guideline for palliative sedation in the Netherlands. J Pain Symptom Manage 2007; 34(6):666-670.
(36) de Graeff A, Dean M. Palliative sedation therapy in the last weeks of life: a literature review and recommendations for standards. J Palliat Med 2007; 10(1):67-85.

Part IV

General discussion

Chapter 9

Introduction

The general objective of this dissertation was to study Flemish nurses' attitudes and involvement in euthanasia and other end-of-life practices. Different research questions were raised at the beginning of the dissertation and will be discussed in this chapter. First, some methodological issues, strengths and weaknesses of the different studies used in this dissertation are addressed. Subsequently, the main findings of the study, while keeping the methodological issues in mind, will be discussed. First, we describe the attitudes of nurses towards end-of-life decisions and towards their role in those decisions. Next, we discuss the findings concerning the involvement of nurses in those practices. In a next part, we continue with discussing the differences between nurses working in different health care settings for both their attitudes and involvement. Finally, some recommendations for practice and policy, and further directions for research are proposed.

Methodological considerations, strengths and limitations

Nu-ELD study

The findings related to the attitudes of nurses towards end-of-life practices and towards their role in it (Chapter 2 & 3) and to their detailed reports about their involvement in physician-assisted dying and continuous deep sedation (Chapter 7 & 8) are based on the Nurses in End-of-Life Decisions study (Nu-ELD study). Major strengths of this study are the large sample size, the random sampling, the high response rates, and the broad range of nurses involved in the study. We did not restrict our study to one or a selection of hospitals, to some specific units, or a particular home care organization. The organization in which nurses work and in which formal and informal regulations and routines exist may influence their attitudes towards end-of-life decisions (1) or may be indicative of their involvement. We included nurses who might be, due to their daily work, confronted with medical end-of-life practices independently of the place where they work. Most studies only asked palliative care nurses (2-5), nurses working in intensive care units (6;7), or oncology nurses (8;9) about their attitudes and/or involvement in for example euthanasia, while home care nurses or nurses who work in a care home can also be confronted with euthanasia. Therefore a federal registration system was used for the sampling of our respondents. Next, we described in our study the practice of different end-of-life decisions instead of using terms like euthanasia or continuous deep sedation. Those terms were particularly avoided because of their value connotations and their use in different kinds of practices. In the attitude survey some statements dealt with euthanasia, but we first presented a clear definition of euthanasia. We also avoided as much as possible the need for the nurse to interpret the physician's intentions, which could not be done for euthanasia as the intention to hasten the death is intrinsic to the definition. We asked the nurse whether the patient was administered drugs with the explicit intention to end the patient's life. Further, the questionnaires have been tested extensively. Content validity was established through expert review, and through an in-depth discussion in a focus group.

Cognitive testing (19) was conducted with 10 nurses in the case of the attitude-survey and with 20 nurses in the case of the involvement-survey to assess comprehension of the question and answer categories and the question wording. Particular emphasis was placed on the classification and the understanding of the nurses of the different end-of-life practices. Finally, these results can be considered representative of Flemish nurses. The results concerning the attitudes of nurses are representative for all nurses who have experience in patient care. The results concerning the involvement of nurses in end-of-life practices are representative for all nurses who have experiences in caring for patients whose treatment at the end of life involved a medical end-of-life decision.

For studying the involvement of nurses in end-of-life practices, we asked nurses to recall their most recent patient for whom an end-of-life decision was made. End-of-life decisions are difficult to study and by recalling a real patient for whom the nurses provided care, it is easier to reconstruct what has actually happened and how they are exactly involved.

The study also has several limitations. First, it is noteworthy that the database of nurses was not fully updated at the recruitment phase. As a consequence, there might be an underrepresentation of younger nurses, which has to be taken into consideration when interpreting some results. Another limitation of the study is that we cannot always make nuanced interpretations of the practice by asking in-depth questions. Especially in the attitude survey, only general statements were presented. It is known that attitudes can vary according to the clinical condition or circumstance (e.g. the age of the patient, the degree of suffering, the opinions of the patient's relatives, the consent of the healthcare team,...) (10-12). Besides, nurses' feelings about euthanasia and other issues surrounding the end of life are complex (13-16). This can also be deduced from the large proportion of neutral answers on some statements (see chapters 2 & 3). It seems that some nurses have difficulties in aligning them towards one direction (acceptance of rejection), perhaps due to the missing of some crucial information in the statements.

For studying the nurses involvement in end-of-life practices, a retrospective design was used. Nurses reported a case that could have occurred some time before filling in the questionnaire, making possible recall or memory bias an important limitation. Although we limited the recall to approximately 12 months, it could not be excluded that the retrospective reconstruction of the end-of-life decision-making and of their own involvement in it influenced their responses. Contiguously and inherent to the design where nurses have to recall their last case, selection bias could also occur. It is possible that nurses who were asked to describe their most recent case, in fact reported their most memorable case or perhaps the case in which their involvement was more extensive. Next, this study does not allow to pronounce upon the incidence of nurse involvement in end-of-life practices, because a patient has in most cases more than one nurse involved in their care, as nurses work in teams providing patient care 24h/24h; different nurses involved in the care for the same patient are likely to be

differently involved; nurses are not always involved in the care of a patient (17); and physicians do not always communicate with nurses about end-of-life decisions or involve nurses in their decision-making (as chapters 5 & 6 indicate).

Another important limitation is that nurses make an interpretation of what is considered a medical practice wherein physicians make decisions. Especially when communication between physician and nurse is not optimal, the nurse may make an interpretation of such decisions. A nurse may know that a large dose of morphine is prescribed or can administer the dose but at the same time not really know what the intention of the physician was. The physician could have intended to relieve the patient's suffering in an aggressive but necessary way, but when this is not adequately communicated, the nurse may assume that the dose is rather high and is intended to hasten the patient's death. Studies have revealed that nurses sometimes have difficulties in distinguishing between different decisions near the end of life (18;19).

Death certificate study

In chapters 5 & 6 secondary analyses were made, based on the death certificate studies among physicians, which use a quantitative and retrospective study design. The strengths and weaknesses of the death certificate studies for studying end-of-life decisions have repeatedly been demonstrated (20-25). Important strengths of this study for studying the involvement of nurses as indicated by the certifying physician are that the incidence of the nurses' involvement can be determined and, as the follow-up studies used identical protocols and questionnaires, trends could be studied in a reliable manner. Specific to our analyses, some limitations must be stipulated before interpreting the results. First, the involvement of nurses could only been studied in a rather limited way. Information was only available about who had administered the drugs in cases of euthanasia and the use of life-ending drugs without the patient's explicit request, and whether the physician had discussed the (potential) life-shortening of the end-of-life decision with other caregivers, where in both questions 'nurses' was one of the answering options. In the Nu-ELD study wherein involvement was studied more in-depth showed that involvement in decision-making can mean different things (chapters 7 & 8). Besides, other perceptions than from the certifying physician, e.g. from the patient, relatives, other healthcare workers or the nurses themselves are not investigated, though research already indicated that nurses and physicians can perceive their involvement in the decision-making process differently (26;27). Therefore, we could not be certain if this reflects what truly happens, and if questioning nurses would have led to other findings. Finally, some results are based on a small number of cases, especially in the case of euthanasia. Prudence is warranted when interpreting these results.

PIC-Nu study

The Paediatric Intensive Care Nurse study (PIC-Nu study) described in chapter 4 also has a quantitative and retrospective study design. Despite the illegal nature of some of the practices concerned, the response rate was satisfying. The

cooperation of five of the seven paediatric intensive care units in Belgium, and the inclusion of all nurses working in those units strengthen the generalisability of our results. A non-response analysis could be done on some of the nurses' characteristics in which no differences were found between the responders and non-responders on sex, age, years of experience, and educational level of the nurses.

As for the limitations, we could not exclude a potential bias in the results due to the non-participation of two units, although no indications exist that those two units differ in their care delivery, size, nurse characteristics, or other factors. Next, attitudes were asked by means of statements and using Likert scales in which subtle distinctions and the complexity of the practices cannot be revealed. A limitation concerning the nurses' involvement in end-of-life decisions is that the retrospective design of the study implies a potential recall bias and selection bias as the nurses were asked to recall the last child in their care whose treatment involved an end-of-life decisions, similarly as in the Nu-ELD study. Further, more nurses may have reported on the same child. However, the study did not aim to measure the incidence of end-of-life practices in paediatric intensive care units. Rather the attitudes of nurses who care for terminally ill children and their involvement were the objectives of the study.

The attitudes of nurses towards end-of-life practices

Attitudes towards end-of-life practices

End-of-life practices in general
In chapters 3 & 4, it was shown that only a minority of nurses (6%) think that physicians should aim at preserving the lives of their patients in all circumstances, even if patients ask for the hastening of the end of their lives. The majority of nurses accept the practice of different types of end-of-life decisions with a possible or certain life-shortening effect, including the alleviation of pain and/or symptoms with a possible life-shortening effect (96%), the withholding or withdrawing of a potential life-prolonging treatment (93%) and the practice of euthanasia for terminally ill patients who have extreme uncontrollable pain or other distress (92%). What is remarkable about this finding is that, next to the general high acceptance rate of all end-of-life decisions among nurses, nurses seem to accept euthanasia, which is considered as an extraordinary medical act, in a similar degree that they accept "non-treatment" or "pain alleviation" which can induce a similar life-shortening effect, but which is not inherently associated with the intention to end the patient's life.

Reasons for these findings can be hypothesized. First, nurses are intensively involved in the care of terminally ill patients and their relatives, more than any other professional group involved (15), and spend a lot of time with them. As a consequence, nurses are directly and daily confronted with the consequences of an inappropriate treatment and with the patient's pain and suffering and that of the patient's relatives, which can not always be alleviated. Hence, nurses may experience a profound wish to end the patient's suffering given the hopelessness of the situation (15;19;28). The perspective of nurses is also characterized by a desire to act in accordance with the wishes of their patients (1). Second, it is important to consider that nurses have no decision-making capacity in end-of-life decisions. In a small-scale study, physicians give different reasons for being for or against euthanasia than do nurses, patients and relatives, because of their specific function as decision-makers (28). Some nurses indicated that they would never want to make such a decision, nor shoulder such a responsibility (29-31). It is easier to accept a practice than to decide to do it and taken full responsibility for it. Third, in Belgium, three important laws, the law on the rights of the patient (32), the law on palliative care (33), and the euthanasia law (34) were promulgated in 2002. Those laws, together with the debates preceding them, probably created a more open and accepting climate about end-of-life practices. Those end-of-life decisions with a possible or certain life-shortening effect has also become more prevalent, which can be seen from the large-scaled incidence studies (35). The acceptance rates of end-of-life decisions among physicians in Belgium have also increased in comparison with 2001 (36;37), and are now very similar to those of nurses. Finally, euthanasia is also legally regulated and accepted in Belgium. It seems that after five years of legislation, the practice of euthanasia for terminally ill patients who suffer unbearably is generally accepted

among nurses and considered as a valuable option next to the other options near the end of life that might shorten the patient's life, though it remains an extraordinary medical act and very strict precautions have to be followed. The practice of euthanasia has also become more prevalent (35;38). The practice is also more publicly debated and covered in courses and training modules, not only locally in healthcare institutions, but also nationally in initiatives such as the LEIF-nurses (Life End Information Forum), a course, organized by a Palliative Care Network, for nurses about euthanasia and other end-of-life decisions.

In comparison with other countries (such as the UK (39), the US (40;41), Australia (42;43), Japan (3), France (44;45), and more) the acceptance of euthanasia in Flanders seems to be much higher, but most of those studies were done some years ago, among particular nursing specialisations, different methodologies were used and other questions/statements were asked. A study performed among physicians in different countries with the use of the same methodology (36), showed that the acceptance of euthanasia and patients having the right to hasten their death was the highest in countries in which euthanasia was legalized or being under debate (in Flanders, the Netherlands, and Switzerland). A study about the acceptance of euthanasia among the general public in 33 European countries also showed very clear cross-national differences which was related to the countries' own tradition and history (46). There seems to be much cross-national differences in the acceptance of end-of-life practices.

Euthanasia

Although most nurses accept the practice of euthanasia for terminally ill patients who suffer unbearably, a majority (70%) also believe that sufficient availability of palliative care could prevent almost all euthanasia requests. Only a minority of nurses are concerned that, by accepting the euthanasia practice, this leads to more life-ending acts without explicit patient request (17%) and harms the relationship between patients and physicians (9%). One fourth (26%) consider continuous deep sedation as a better alternative than euthanasia.

In the development of the euthanasia law, it was proposed to install a palliative care filter (47), which was not done in the end. A large proportion of palliative care nurses do regret that this was not done (48). A palliative filter procedure is, however, integrated into more than 80% of the written ethics policies of Flemish Catholic hospitals and care homes (49) which may also have contributed to a high percentage of nurses believing in the value of this filter. In a review by Verpoort et al. (15), it was suggested that belief in the possibilities offered by palliative care is for nurses an argument against euthanasia, which is not fully supported by our study. Nurses may believe in palliative care as a prevention for euthanasia requests, but this does not automatically mean that they don't agree with euthanasia being an option for those who request it. Studies already stated that palliative care and euthanasia do not seem to contradict (50;51).

Studies have showed that the most important aspect of accepting euthanasia is the fact that patients are suffering (1). The alleviation of pain and suffering is the nurse's primal concern (30), and when this cannot be alleviated, nurses believe that life-ending is a justifiable option (31). This might be the justification for the nurses' rather high acceptance rate (57%) that physicians should be allowed to end the life of terminally ill patients who suffer unbearably and are not capable of making decisions. Some studies using vignettes with an experimental design showed that nurses merely believe that an explicit request is required to accept the use of life-ending drugs (10;11;52); however, our study clearly shows that 57% of nurses would also accept the practice without the patient formulating an explicit request. Among the nurses who reject life-ending without request are many head nurses and nurses working in management functions. Their distance from direct confrontation of the patient's suffering may explain this rejection. A recent study found that head nurses were found to follow more often a procedural, action-focused perspective in dealing with euthanasia requests, in which they prefer to follow the procedural protocols. Bedside nurses are more likely to follow a more existential-interpretative perspective (53). In the latter, nurses are more practice-driven and act on their personal involvement in the case, and place less importance on the legal requirements.

Further, studies suggested that fears of abuse are indicative for a negative attitude (18;28). Nurses would fear that a euthanasia law would lead to an escalation of the performing of end-of-life acts without the explicit request of the patient (18); however, this study does not confirm this. There has been much debate about the slippery slope from voluntary to non-voluntary euthanasia (54), but only a minority of Flemish nurses fear such abuse and as they are frequently confronted with and stand in the middle of such practices, this information is important for lay persons dealing with this issue. It is also important to note that Flemish nurses work in a country wherein euthanasia is legalised and they possibly speak from own experiences. Nurses who work in countries without any legalisation will probably still fear such consequences.

In some studies, it is claimed that the use of drugs to put the patient into a coma until death, i.e. continuous deep sedation, is a good alternative to euthanasia (31;55;56). Palliative care nurses especially tend to take this position (31). It has also been promoted within Flanders as an ethically superior alternative to euthanasia, especially by opponents of euthanasia (57). Some health care institutions in Flanders even favour a policy of supplanting euthanasia with continuous deep sedation and in the Netherlands it has been suggested that this practice is already going on (24). In our study, the majority of nurses do not consider the two practices as alternatives, such as euthanasia and palliative care are not considered as alternatives.

Variations between nurses

Some personal and work-related factors were found to influence the attitudes of nurses, though not consistently across all the different statements. It is remarkable that a particular group of nurses do not have consistent opinions for

or against life-ending in general, pointing to the complexity of end-of-life practices. A relatively consistent factor found is religion. The age of the nurses and their having had some training in palliative care also contributed to the way nurses agree with particular practices near the end of life, though not systematically over all the statements.

Religious affiliation was confirmed as a strong determinant of a nurse's attitude towards euthanasia (15;43;58). Religious nurses and especially those who are Catholic and rate their religion as important in their professional attitudes towards end-of-life practices, agree less often with euthanasia than do non-religious nurses. We were also able to demonstrate that this counts for attitudes towards life-ending in general and for their belief in the preventative force of palliative care and their conviction of possible negative consequences associated with euthanasia. Interestingly, attitudes towards withholding/withdrawing life-sustaining treatments and intensified symptom alleviation were not related to being religious or not, although those decisions may also hasten the patient's death. In Catholic doctrine, euthanasia is considered morally wrong, and withholding/withdrawing life-sustaining treatments and intensified symptom alleviation can be consonant with Catholic (or other religious) principles (59). Cohen and colleagues (60) found a similar non-relatedness among physicians in the two latter practices. They explained the finding as being in accordance with their religion's acceptance of the human condition and inevitability of death (death must be accepted and life does not have to be maintained by technological means), of the use of considerations of compassion and of the doctrine of double effect. However, notwithstanding the higher rejection rate among Catholics in comparison with non-religious nurses, a majority of Catholic nurses also accept euthanasia, as well as a proportion of nurses who rate their religion as important in their professional attitudes towards end-of-life practices. Many nurses do not let their religious convictions determine their acceptance of euthanasia.

There were also differences in some attitudes between older and younger nurses. Older nurses are more likely to agree with the practice of continuous deep sedation and that it is a preferable alternative to euthanasia, with the administering of life-ending drugs to patients who are suffering unbearably and not capable of making decisions, and that good palliative care prevents euthanasia requests. All these statements actually deal with pain and symptom alleviation. Different studies have put forward hypotheses that are in line with our findings, such as: being younger tends to go together with feelings of anxiety about the administering of pain medication and sedatives to terminally ill patients (1); older nurses have more experience with situations wherein pain can not always be alleviated and therefore tend to accept it based on their personal experience (31); older people place less importance than younger ones on patients formulating an explicit request or repeated requests for euthanasia in accepting euthanasia for a patient (10;11); younger nurses, on the other hand, support legalizing of euthanasia more (29;43); younger nurses more often follow strict procedures while older ones have more experience in getting in the

personal story of the patient and will go more on their feelings (53). Due to the design used, it cannot be determined from this study whether the age difference is due to greater experience among the older nurses or to a cohort effect, i.e. a difference between younger and older generations (43). In the first, nurses may rely more on their experiences for many years that for example in cases of unbearably suffering an urgent solution must be taken that not always correspond with legal regulations. Examples of the latter are a different societal context, and/or other emphases in nursing education. The older generation nurses have been more educated within a caring culture with less emphasis on patient autonomy, legislation and rules than the younger generation.

Finally, having had some palliative care training was independently associated with a higher acceptance of non-treatment decisions and of good palliative care being a prevention for euthanasia requests, and a lower acceptance of the administering of life-ending drugs without explicit patient request. In palliative care training, attention is given to medical futility, the pharmacology and indications of drugs, the possibilities of palliative care, effective treatment of symptoms near the end of life, and the discussion of ethical and legal topics. Palliative care emphasise the pain and alleviation and letting people die a natural death, and avoid the shortening of a patient's life.

End-of-life decisions for dying children
Most nurses in Paediatric Intensive Care Units (PICU) agree that continuation of treatment is not always in the interest of the child (90%) and that forgoing treatment is justified in some cases (92%). Most think that considerations about expected quality of life should be taken into account (90%) and that parents should be involved in decision-making. Only a minority of nurses found it always ethically wrong to hasten the death of a child by administering lethal drugs (6%) and a considerable proportion would be willing to cooperate in it (78%). Most of the nurses were also convinced that the law should be adapted so that life-termination of a terminally ill child would be possible in some cases (89%).

As nurses in general are highly acceptable of non-treatment decisions for patients, PICU nurses also think this should be an option for terminally ill children. However, due to the age of the child, specific considerations are important in accepting or rejecting end-of-life care options that might hasten a child's death, such as the best interest standard, future quality-of-life and the parent's involvement, which paediatricians also seem to follow (61). It could be stated that the high acceptance among nurses, as mentioned earlier, is the consequence of them having no decision-making authority at all, which makes it somewhat easier to accept these things. It is known that making decisions in the best interest of a child or estimating the future quality of life which result in the child's death is very difficult (62;63). However, very similar results were find in the study performed among paediatricians (61). It seems that physicians and nurses who work with terminally ill children have similar attitudes towards end-of-life decisions, which was also found in foreign studies (64;65).

Although the administering of drugs with the explicit intention to hasten death is not allowed among children, we found that most PICU nurses could accept it and are even willing to cooperate in it. PICU nurses are very concerned with the care of the child and have to support their families. As they stand in the centre of the care for such children, this might indicate that in some cases the only way to help terminally ill children is to help them die. An important aim for nurses is the prevention of unnecessary suffering and this justifies in some cases the use of life-ending drugs, although this is legally not allowed. Most of the nurses are therefore also convinced that the law should be adapted so that life-termination of a terminally ill child would be possible in some cases.

Attitudes towards nurses' role in end-of-life practices

End-of-life practice in general
Among Flemish nurses there is a general agreement that nurses should be involved in the whole process of end-of-life decisions because of their central role in the care of the patient (90%). In particular, most nurses are convinced that when the physician makes such a decision it should be discussed with the nurses involved (89% in the case of administering life-ending drugs and 78% in the case of non-treatment decisions). Two thirds (67%) also agree that patients would rather talk about end-of-life decisions to nurses than to physicians.

Different studies are in line with our findings. Some small-scale qualitative studies point to the relevance of nurses' involvement in the whole process of end-of-life practices (2;66;67). In the Netherlands, nurses also indicated that they want to be involved in end-of-life decision-making (68). Nurses are the people who frequently care for patients in their most intimate sphere. While they are nursing the patient, they are physically very close. They are always present, especially in hospitals and care homes, and therefore well-informed about the patient's wishes, troubles and questions. Physicians often have little time and see the patient less frequently. As physicians are the ones who have to make complex and difficult end-of-life decisions, the information nurses can provide, could contribute to more detailed and considered end-of-life decision-making. It seems that most nurses clearly recognize the unique position they hold between the patient and/or relatives and the physician.

There is more variation in nurses' opinions about whether physicians are prepared to listen to their opinions about end-of-life decisions (50% agree, 21% disagree) and whether nurses find themselves in a hierarchically subordinate position which makes communication about such decisions difficult (35% agrees, 41% disagrees). Those findings lead us to conclude that not all nurses consider the relationship between medical and nursing groups as optimal, that some seem to struggle with communicating with physicians about end-of-life decisions, which could lead to a great deal of dissatisfaction in their daily routine. This could be an impediment in the delivery of high quality end-of-life care for terminally ill patients. For nurses who feel powerless to expound their opinions due to their subordinate position or to an unwillingness on the part of the physician to listen

to their opinions, as has been found in other studies as well (69), it seems that relatively little optimism exists about nurses having an important role in end-of-life practices and more specifically in the physician's decision-making process. Those nurses seem to blame their non-involvement on the physician's unwillingness to involve them. However, nurses being more assertive and skilled in communication would very likely lead to a higher willingness of physicians to listen. Further, we did not find any association between this experience of being in a subordinate position with the nurses' personal or work-related characteristics that we studied. It could be that the personal experiences of nurses of their contact with some physicians may be an important factor. Studies already indicate that not all physicians in Belgium discuss issues related to end-of-life care with their patients (70), and large differences are also found between groups of physicians (71). Hence, it is not surprising that not all physicians communicate with or listen to nurses about end-of-life decisions to the same extent. The experiences nurses have had might determine how they perceive the physician's readiness to listen or their position in the physician-nurse relationship.

Euthanasia

The role nurses see for themselves in euthanasia is different according to the different stages in the euthanasia process. In the first stage, the request for euthanasia, more than half (61%) of nurses think that a patient will address his/her request for euthanasia more often to a nurse than to a physician. This could be the consequence of nurses believing to have a caring attitude that creates an atmosphere in which patients feel free to put forward their request (67). Next to their specific caring role, nurses also stand out in their expertise and comprehensive approach. Nurses may be more open than physicians to the spiritual and existential dilemmas patients are dealing with at the end of their lives (such as how patients find meaning, achieve life goals, and finding life worthwhile) (72-75) which possibly makes the patient more at ease in discussing the topic of euthanasia with them. However, there is no sound evidence in the literature that patients in general would rather formulate their requests to nurses than to physicians (76), and to whom patients regularly pose their wishes to seems to be very dependent on the particular healthcare setting or specialty (77). Further, most nurses (90%) are convinced that physicians should discuss a request for euthanasia with the nurses involved. It seems that their unique position towards patients and relatives and their specific expertise can provide the physician with valuable information in order to come to a decision. Perhaps, nurses consider it as sufficient that the physician at least informs them. Details about how nurses see that particular involvement cannot be deduced from this study and could be understood differently by the nurses, though what can be inferred is that nurses consider it important that there is communication about euthanasia requests between the physician and the nurses involved. It seems also obvious that such a request is discussed within the health care team providing the further care for the patient. Third, concerning participation in the performance of the euthanasia, we found that, although only a minority of nurses (16%) think that the administering of drugs in euthanasia is a task for nurses to

perform, a considerable group (43%) would in some cases be prepared to administer them. Some foreign studies already revealed that a considerable proportion of nurses would be willing to be involved in the provision of euthanasia (15;29;40). Nurses worldwide seem to be highly acceptant towards being involved in the performance of euthanasia of which most of them are willing to remain with the patient during the act of euthanasia; they want to support the patient and his/her relatives (15). Some nurses see their involvement as more far-reaching and are in some circumstances willing to administer the drugs themselves although they are – according to current Belgian law – not allowed to do so (34). From our study we could not determine in which circumstances they would. In the literature, we find that nurses would be willing to administer the drugs if a physician requested them to, which conforms with our findings that home care nurses are less prepared to administer life-ending drugs (see chapter 3). In home care the delegation of such acts is less common (see chapters 5, 6 & 7). Other hypotheses are that nurses are only willing to administer drugs when the suffering is obvious to them (as mentioned earlier), or when the patient explicitly wishes that they perform the act, or if they consider that they are technically more competent to perform it than the physician (78). Finally, it is also important to note that nurses who care for terminally ill children are also prepared to cooperate in the administering of life-ending drugs which is in principle doubly illegal (life-ending of terminally ill children and nurses administering the drugs). In conclusion, legal restrictions do not hold nurses back in their willingness to help terminally ill patients, including children.

Variations between nurses

Some personal and work-related factors were found to influence the attitudes of nurses towards their role in end-of-life decisions, though not consistently across all the different statements. The most consistent factor is the setting in which nurses work, which we further consider on page 200, as large differences were also found in their actual involvement in end-of-life practices. Next, remarkable differences were found between male and female nurses in their willingness to administer drugs with the explicit intention to end the patient's life. Similar differences were found based on their religion.

Female nurses (the vast majority of our sample) are less inclined than male nurses to administer life-ending drugs, and to consider it as a task that nurses are allowed to perform. They also believe more often that the task of nurses in euthanasia is restricted to patient and family care. This reluctance or reserve in female nurses and the far-reaching role fulfilment in male nurses could be a result of a more care-orientated vision in females and a more act-orientated vision in males. It can be questioned whether or not gender-stereotypes also prevail in nursing.

We also found that religious nurses who rate their religion as important in their professional attitudes towards end-of-life practices are less willing to administer life-ending drugs in case of euthanasia. This is in line with their lower acceptance of euthanasia in general. However, it is important to mention that in chapter 7, it

was found that these factors did not have an influence on the actual administering of life-ending drugs in practice. Also Catholic and other religious nurses had administered life-ending drugs, as did those who rated their religion important in their professional attitudes towards end-of-life practices. A study performed among physicians also shows that religious beliefs influence their views on end-of-life decisions, but less so their actual decision-making when dealing with real patients and circumstances (60). Apparently, nurses are capable, to a certain extent, of setting aside their own religious convictions in order to meet the needs of patients (9;15;79).

In closing this part on the attitudes of nurses, we would like to mention the considerable proportion of nurses giving neutral answers on a range of different statements. We also mentioned this in the limitation section of the Nu-ELD study on page 175 and explained this by methodological reasons (the use of a Likert scale, in which the respondents are asked to place them in a black or white position without specifying the context). Additionally, the high rate of neutral answers could also be the consequence of the limited experience of the practice of some nurses. Ten per cent of the sampled nurses had no experience at all of caring for patients at the end of life and only half had had experiences with end-of-life practices in the last 12 months. It is difficult to accept or reject a practice or a nursing role in a particular practice without having had experience of it. Next, the high proportion of neutral answers can also be the consequence of the fact that people who stand in subordinate positions are more reluctant to express their opinions about practices that strictly speaking fall outside their social recognized qualifications (80). Finally, note should be taken of the low percentage of neutral answers on the statement dealing with the acceptance of euthanasia, although it was found in other studies that nurses have difficulties in giving a black-white answer in that particular case (13). However, the statement provided some detailed information on the circumstances in which euthanasia is acceptable, as stated in the euthanasia law, which is also highly debated.

The involvement of nurses in end-of-life practices

End-of-life practices in general

In a previous part, we discussed the evidence that nurses want to be involved in discussions about end-of-life decisions; yet in practice they may be frequently disappointed as physicians often make such decisions without consulting them (see chapters 5 to 8). The death certificate study among physicians in 2007 showed that in 49% of the end-of-life decisions, the physician did not consult a nurse. Given the arguments mentioned in the previous paragraphs about the important contribution nurses can make to end-of-life decision-making, this percentage is rather low.

Unfortunately, the reasons for not consulting a nurse in end-of-life decisions have not been studied and can therefore only be hypothesised. Factors such as the patient not wishing nurses to be involved, the lack of necessity of consulting a nurse because everything was clear, willingness to safeguard confidentiality and privacy, lack of time, the conviction that medical end-of-life decisions is a medical affair, that nurses may not always be available or involved in the care, are possible reasons identified from the literature (78;81). Additionally, some background characteristics of nurses were also related to a higher involvement in decision-making (68;82). From the death certificate study we could infer that no differences exist according to the act performed in the end-of-life decision as such (administering drugs, withdrawing or withholding life-prolonging treatment), but this consultation is clearly more frequent when the physician acts with the (co-)intention of hastening the patient's death in comparison with other decisions. We also found that the consultation rate is the highest in care homes, followed by hospitals and is the lowest in home care. Additionally, particularly in institutions, nurses were more often consulted when the patient is less well educated. In chapter 6 hypotheses for these findings were given. From the chapters 5 to 8, we can conclude that there seems to be a large variation in nurses' involvement in decision-making and explanations for this must be found in the characteristics of the health care setting, the physician, the nurse, the patient, and the decision made. Further, we should be aware that physicians and nurses may perceive being involved in the decision-making differently, as previous studies also found (26;27;83). It is likely that physicians indicate that nurses were consulted while nurses do not perceive this as such. Being consulted or being involved in decision-making can also mean different things (see chapters 7 & 8).

Euthanasia

In the following the results about nurses' involvement in euthanasia will be discussed, generally over different health care settings. In a next paragraph, the important differences between health care settings will be discussed. Here, we further discuss our findings according to the different stages in a euthanasia process.

Patients requests
Studies often assumed that, because nurses are close to patients and care for them on a daily basis, patients would rather put their request for euthanasia to a nurse than to a physician. More than half of nurses are also convinced that this is the case. In chapter 7 it was found that the patient had expressed their euthanasia wishes to 69% of the nurses who cared for a patient who received euthanasia. A quarter (24%) of nurses revealed that the patient had told them their wishes before telling the physician. In a recent Dutch study, patients revealed their wishes sometimes to nurses, sometimes to physicians, depending on the sector, the relationship between the physician and the patient, the relationship between the nurse and the patient, the accessibility of both, etc. (76). Patients posing their requests to nurses is not peculiar to the countries in which euthanasia is legal and thus supposedly more discussible (2;67;76). In countries where euthanasia is not allowed, patients also formulate their requests for euthanasia to nurses (3;6;8;29;30;84), indicating that nurses worldwide must acknowledge their important function in hearing euthanasia requests.

Notwithstanding with whom the patient talks first, both the medical and nursing profession should be aware of possible signs and requests for euthanasia from patients, and have to fulfil a function of active listening. Further, specific to nurses, as they stand between the patient and the physician, they can have a very determining role in how that request is further handled. Nurses have a key function in which they can determine how much attention is given to it, but also in interpreting the request, and adequately communicating those signs, interpretations, and convictions to the treating physician who further has to deal with the request (2;67). Their steering function during this phase may not be underestimated (85).

Decision-making process
The death certificate study showed that physicians consulted nurses in 54% of all euthanasia cases in 2007 (chapter 5). In the study in which the nurses who cared for a patient receiving euthanasia were questioned, they indicated that in 64% of cases the physician had involved them in the decision-making (chapter 7). Comparing those two percentages is not appropriate, as the difference between the two is most likely to be the consequence of a different methodology and a different construction of the variable, but will also depend on the fact that nurses are not always involved in the care of a terminally ill patient (17), nurses may not always be acquainted with all euthanasia cases, and nurses and physicians perceiving this consultation differently. What is certain is that not all physicians discuss a euthanasia request with the nurses involved. Hence, questions emerge as to whether nurses can work satisfactorily in the role physicians allocate them (we further will see that nurses often have a role in preparation of and during the euthanasia performance), without first involving them in the decision-making process.

As far as it concerned the context of this involvement, we found that nurses more often provide information about the patient's condition or the wishes of the patient and relatives than that they make the decision on euthanasia together with the physician or give their personal opinion about the euthanasia request. Nurses can fulfil different role conceptions. First, physicians can perceive nurses as an important source of information, not only about the patient's physical or mental condition, but also on his/her wishes, the endurance of the request, etc. As our study also revealed that patients frequently talk with nurses, evidence exists that nurses dispose of this crucial information. Second, nursing also includes promoting the patient's interest, being the patients' and relatives' advocates (1;69;86-89). Third, nurses also develop a specific care expertise, which is different from the expertise physicians develop, which is a fundamental reason for physicians to ask nurses for their opinion about the difficult decision they have to make. Physicians often discuss such a decision with colleague-physicians (24;90), but this will be mainly from a perspective which is identical to theirs. Reaching decisions by taking different perspectives into account could optimise the quality of their decision-making. Finally, shared decision-making in which physicians and nurses decide together, is likely to contribute to the quality of the care patients and relatives receive during the last phase of life (91). A shared decision between those involved in the care will assure that both the medical and nursing perspective is taken into account and a decision is made which those involved in the care can fully support. We can conclude from our study that the role of nurses in decision-making is mostly restricted to the role of nurses being information providers, and that a more extensive role is particularly open to improvement.

Notwithstanding the rather low involvement in decision-making, physicians performing euthanasia tended to discuss the practice with nurses more often in 2007 (54%) than in 1998 (30%) which lead us to conclude that the involvement of nurses in decision-making has increased since the enactment of the euthanasia law, perhaps as a consequence of physicians being more aware of and wanting to follow the procedural requirements of the law that prescribes that the euthanasia request has to be discussed with the nurses involved. As we see a higher consultation rate in all kinds of end-of-life decisions (chapter 5) we may assume that this requirement has made a positive contribution towards communication between physicians and nurses in end-of-life practices in general. But is the higher consultation rate the only consequence of that requirement of the law? In the Dutch euthanasia law, the consultation of nurses is not a legal requirement, and similar consultation rates have been observed between Flanders and the Netherlands (76), rather indicating that nurses are consulted for other reason than the legal requirement alone. Perhaps the law has not only made euthanasia publicly more debatable, but has had also a positive influence on making the topic being discussible within the healthcare setting (57). However, it is difficult to draw these conclusions from our figures. It could similarly be possible that the increase in involvement is the consequence of younger groups of nurses being more emancipated and assertive about being involved in decision-making (92), as our study also showed that younger nurses

are more often involved in decision-making (chapter 7). Older nurses are perhaps accepting of the more traditional physician-nurse hierarchy in which nurses follow a physician's orders and care for their patients without speaking out for the right to be involved in decision-making (93).

Assistance in performance
One out of three nurses caring for patients who receive euthanasia is present during the euthanasia act and nearly all of those have some supportive role, mostly to the patient and/or relatives. Supporting the patient and his/her relatives is a typical role nurses fulfil which is part of their caring role (14) and which is also legally incorporated into a royal resolution stating that "rendering terminal care and support in the handling of the mourning process" belongs to nursing practice (94). Next, nurses also distinguished themselves by their technical competences and skills. Those tasks of nurses in their daily practice seem to continue when euthanasia is being performed. Four out of ten nurses have practical preparatory tasks in the actual administering of the life-ending drugs (e.g. receiving the drugs from the pharmacist, the preparation, control, setting out, and passing of the drugs to the physician). Under normal medical circumstances, those kinds of actions are not problematic and fall under the tasks of nurses, but in the case of euthanasia, which is an exceptional medical action, it is not clear which tasks should be performed by physicians and which could be done by nurses. Discussions are being held about which preparatory tasks can be seen as part of the actual performance of euthanasia and which can be seen as isolated from the act and therefore possibly considered as nursing tasks. The only explicit reference of this is made in an amendment to the euthanasia law that regulates the role of the pharmacist which states among other things that the pharmacist has to deliver the prescribed drugs personally to the physician (95) which is clearly not always followed in practice (in 21% of cases the nurse received the drugs).

Administering the drugs
The death certificate study showed that in 27% of all euthanasia cases occurring in 2007, physicians reported leaving the administering of the life-ending drugs to nurses. In the study among nurses, 12% of nurses who cared for a patient who received euthanasia indicated that they had administered the drugs explicitly intended to end the patient's life. In most cases, nurses administered opioids (64%); in some cases, nurses administered neuromuscular relaxants and/or barbiturates (36%). Although the administering of the drugs in euthanasia falls under the responsibility of the physician, it is quite often done by nurses.

In order to discuss our findings, we like to focus on the fact that there seem to exist two kinds of euthanasia practice (38). The first practice involves the administering of opioids with the explicit intention to end the patient's life, which is frequently done by the nurse, and which is mostly not considered or labelled by physicians as euthanasia, and is less often reported to the Review Committee. Those practices can be considered as less clear-cut euthanasia cases where we are perhaps finding ourselves in a grey area in which there are no clear

distinctions between euthanasia and compassionate, aggressive alleviation of pain and suffering. This kind of practice may be considered an easier or more acceptable way to end life, though it is not the appropriate way. In those cases it comes down to euthanasia, though opioids should not be used due to their doubtful lethal effect and potential side-effects which is why they are discouraged for use in cases of euthanasia (24;96). However, our study clearly shows that nurses administer opioids with the explicit intention to end the patient's life. Important to mention is that opioids are frequently given to terminally ill patients in their last phase of life, though in most cases no life-shortening intention or effect is associated. Nurses are responsible – on physician's orders – for administering these kind of drugs for relieving the patient's pain and/or suffering, as stated in the law on palliative care (33). Hence, it is not surprising that nurses administer the drugs in such cases, although they are not allowed to when they are explicitly intended to end the patient's life. It is likely that nurses perceive this particular administering as an extension of the acts they were already performing, and have no objections of doing so. The act of giving opioids remains the same, while the intention between giving opioids for pain and symptom alleviation and giving opioids in order to end the patient's life, is clearly of fundamental difference. A next point that deserves attention is that, regardless of the intention to hasten death, it has been highly discussed whether the use of opioids in terminally ill patients has a life-shortening effect. Myths exist about the power of morphine to lead to death in terminally ill patients (16;97) and studies shows that the effect of opioids is often overestimated by nurses as well as by physicians (98;99). Following on from this, we may wonder whether nurses are interpreting the situation correctly. Had the physician also intended to end life when s/he ordered the nurse to administer opioids? Especially when there is suboptimal communication between physicians and nurses, confusion and misunderstanding can arise. There is no information in our study about the dosage used and any increase just before death, nor whether the dose was higher than needed to alleviate the pain, symptoms or suffering to confirm or refute this hypothesis. In the literature, it has already been suggested that nurses sometimes have difficulties in distinguishing between different forms of end-of-life practices (19;100;101). However, arguments to refute this last hypothesis are that physicians also report the use of these drugs with the explicit intention to end the patient's life (24;90;99;102) and that they also sometimes experience the same difficulties in distinguishing different end-of-life practices (38;103;104).

The second group of practices involves the use of neuromuscular relaxants and/or barbiturates, mostly given by the physician, reported to the Review Committee, and in which due care criteria are likely to be followed (38). This group seems to include the more clear-cut euthanasia cases wherein the requirements of the law are being followed. However, the nurses in our study also reported they had administered neuromuscular relaxants and/or barbiturates which is in contradiction to the precautions the law demands. The reasons given in other studies include the physician's insufficient experience in managing the infusion, the physician's wish, the nurse considering it as a part of

normal nursing procedure, hierarchical physician-nurse relationships, etc (14;77;105;106). Following the law, the administering of drugs falls under the responsibility of the physician. The illegality of the nurses' actions is, however, more pronounced in these cases compared with cases in which opioids are used where confusion of intentions and responsibilities might arise. However, in both cases nurses risk both criminal prosecution and disciplinary measures.

There is, however, a positive evolution in nurses administering life-ending drugs, which has decreased from 40% in 1998 to 27% of euthanasia cases in 2007. We can assume that the law has had a positive influence on the carefulness of the practice. It seems that it is now become more clear what euthanasia exactly is, which drugs are to be used and that the physician has to administer those drugs. Formerly, opioids were being used in order to hasten the dying process which is clearly in part being adopted in legal euthanasia (90). By stating this law, the carefulness of the drugs used has increased with therefore possibly a lower involvement of nurses in the administering. However, as nurses still administer those drugs in a quarter of cases, there remains a large amount of work to be done. We wonder whether all nurses are fully aware of the illegality of their administering of drugs explicitly intended to end the patient's life. It seems that a large group of nurses are not familiar with what is and is not allowed in the case of euthanasia, as nurses themselves state (chapter 3); perhaps more importantly, nurses who administer opioids explicitly intended to end the patient's life do not always consider this as euthanasia, and consequently they may not consider that the euthanasia law covers these actions.

Administering life-ending drugs without explicit patient request
The administering of life-ending drugs without the explicit request of the patient often involves terminally ill patients whose general condition suddenly and drastically deteriorates, leaving them permanently unable to communicate (90;107). Physicians also indicate that life was often shortened by less than 24 hours suggesting that most of the patients were at the very end of life. In these cases mainly opioids are given in order to alleviate suffering, but at the same time the end of the patient's life was intended (90).

Decision-making process
Our study shows that nurses play an important role in this kind of practice. In the decision-making, a similar involvement is seen as in euthanasia. As communication with the patient is often no longer possible, it may be assumed that the physician is more likely to seek information about the patient's wishes or request the opinion of the nurses than in cases of euthanasia where communication with the patient is central. This assumption is not confirmed by our data. Besides, there was also little communication between the nurse and the patient about the administering of life-ending drugs, indicating that nurses may also lack information about the patient's preferences about this particular practice. Another reason for assuming that nurses would be more involved in decision-making in cases of life-ending without explicit patient request than in

euthanasia is their higher involvement during the administering of the process, which is also not confirmed.

For both euthanasia and the administering of life-ending drugs without the patient posing an explicit request, we also studied whether particular groups of nurses were more or less often involved in decision-making. There is a great variation in nurses' involvement in the use of life-ending drugs between care settings which we will further discuss in a following paragraph. Next to those differences, we found that younger nurses are more often involved in the physician's decision-making than older nurses. Similarly as in differences found between younger and older nurses on some statements on the acceptance of end-of-life practices, our study design can not determine whether this is the consequence of a cohort effect or of a changing involvement with growing older. However, it is likely that younger nurses are perhaps more assertive. In society and in health care in particular, patients are being more emancipated and assertive, but so are the nurses who care for those patients (92) which is perhaps translated in a more assertive behaviour towards physicians. Older nurses perhaps work further in the more traditional physician-nurse hierarchy in which nurses follow physician's orders and care for their patients without speaking for the right to be involved in decision-making (93). In the case that the greater involvement of younger nurses as compared to older ones is a cohort effect, the involvement of nurses in the physician's decision-making process is likely to increase in the future.

Administering the drugs

During the administering of the drugs, nurses fulfilled a more extensive role than in cases of euthanasia. Nearly half of nurses administered the drugs and in the incidence study among physicians, it was estimated that the drugs are given by a nurse in 52% of cases. This could be explained by two important factors. First, their higher involvement could be the consequence of the higher use of opioids in this practice (90) and the close resemblance with the alleviation of pain and suffering where the drugs are not intended to hasten death, as Rietjens and colleagues (107) also assumed from empirical research. Again, it is likely that nurses perceive this particular administering as an extension of the acts they were already performing, and have no objections of doing so. Second, physicians had indicated that the reasons for deciding on this practice are the wishes of the relatives, the unbearableness of the situation for the relatives, and the consideration that life should not be needlessly prolonged (90). The practice might be the consequence of health care professionals acting on the suffering of the patient and the relatives in which the latter request to end this suffering. When morphine is introduced, it can for relatives (and perhaps for nurses) last longer than expected which can induce a lot of distress for the relatives who will in the first place address themselves to the nurses who are usually present (85). It has been suggested that nurses, because they are so closely involved in the situation of the patient and the sorrow of the relatives, may identify too much with the situation (76) and rely on their experiences and feelings of impotence, which perhaps make them more willing to administer those drugs explicitly

intended to end the patient's suffering and life. Next, it is equally possible that nurses perform those life-ending acts because they are ordered by the physician to do so. The labour relation between physicians and nurses is characterized by nurses being subordinate to physicians. Nurses are dependent on their superior and it is likely that they perform those life-ending act simply because they are being asked.

Notwithstanding the reasons that nurses are willing to cooperate in these practices, by administering the drugs explicitly intended to end the patient's life without explicit request, they run the risk of being liable to prosecution and the fact that nurses acted on the orders of physicians does not discharge them from possible conviction. Especially in the case of opioids, we are – again – finding ourselves in the grey area between life-ending acts and proportionate pain and symptom alleviation. We can deduce from the jurisdiction (108) and from empirical studies (97) that in most cases the use of opioids is not lethal, on the condition that they are given in proportion to the pain and/or suffering of the patient. When they are given in a disproportional way and are explicitly intended to hasten death, then nurses can, along with the physician, be hold responsible for their actions and must fear legal sanctions. It is clear that a physician or a nurse who deliberately and in full knowledge administers an overdose in order to end the patient's life, and who is therefore unconcerned about adequacy and proportionality, is engaging in a form of illegal life-ending, and not pain control (109).

Next to the higher administration rate in cases when the patient poses no explicit request, we found that there were differences between nurses in their administering of life-ending drugs explicitly intended to end the patient's life (chapter 7). First, nurses who had recent experiences with end-of-life practices have an increased likelihood of administering drugs explicitly intended to hasten death. It seems plausible that physicians consider nurses who have more experience with such decisions as being more experienced and as having the technical and professional requirements to administer the drugs, which increases the likelihood of them doing so. Next, female nurses working in hospitals were nearly six times and male nurses working in hospitals were 40 times more likely to administer the drugs than nurses working in other settings. Our attitude study already revealed that hospital nurses are more likely to consider the administering of life-ending drugs as a nursing task and that male nurses are more willing to do so (chapter 4). These attitudes translate into an effectively higher administering rate among male nurses working in hospitals. As the nursing profession is currently becoming more masculinised, more attention should be given to the consequences for nursing practice concerning end-of-life care. Finally, nurses more often administered the drugs in cases involving frailer patients who can no longer communicate and those older than 80 years. Studies have shown that physicians are giving less assistance in dying when dealing with older patients (110) and that a request for euthanasia was more often not granted by the physician in cases of older patients (111). Physicians who are particularly educated in curing, have perhaps more often an attitude of 'nothing

left to do for them' when dealing with older people and therefore shift more tasks and responsibilities to nurses who take the further care of those older patients.

Continuous deep sedation

Nurses who care for patients who receive continuous deep sedation, i.e. the administering of drugs to keep the patient in deep sedation or coma till death, are highly involved in this end-of-life practice. In this practice in particular they have an extensive role in the performance of the decision (e.g. administering the sedatives, the intensive follow-up of the patient's condition), which may last several days. During this time there is an intensive contact with the patient and his/her relatives. As nurses continue to care for the patient, it seems important that they have also been involved in the decision-making. Our study shows that relatives frequently communicate with nurses about their wishes about continuous deep sedation. They do so more often than patients do, but the patients are not always able to communicate due to their deteriorating condition (112-114). Not only do nurses have information on these wishes, their expertise in observation, measurements, and registration of symptoms could help the physician in determining the refractory character of the symptoms etc. Therefore, nurses may have an important contribution to make to the physician's decision-making in which the relatives' opinions should also play an important role (115). Nurses indicate that in somewhat more than half of the cases they were involved in the decision-making which also raise the chances of their being positive about the cooperation with the physician. Nurses most often evaluated the cooperation as positive when their personal opinion about the sedation was asked. This clearly shows that nurses want to be involved in the decision-making and see their role as going further than merely providing information and being the administrators of decisions made by physicians.

Nurses see continuous deep sedation as a complex issue. We can deduce this by different findings: 1) most nurses think that the decision to use continuous deep sedation was made partly or explicitly with the intention to hasten the patient's death, and had a possible or certain life-shortening effect (chapter 8); 2) in some cases there were disagreements between different people involved in the decision, and in some cases nurses had objections to the sedation and refused to perform certain tasks (chapter 8); 3) there were many neutral answers and disagreements on the attitude statements dealing with continuous deep sedation (chapters 2 & 3); 4) a considerable group of nurses would be in no case prepared to administer drugs in continuous deep sedation (chapter 2). Guidelines about using continuous deep sedation in practice (115;116) and the literature about the practice (117) all point to it being normal medical practice and clearly distinguishable from the termination of life. Clearly nurses have difficulties in recognizing this practice as such. There is a lot of debate about whether the practice can be clearly distinguished from practices where death is intended (118-121). As nurses are in the centre of the practice – they are nursing the patient while the sedation is being performed, they administer the drugs, they are close to the relatives – importance should be given to their

opinions about it. Besides, there is a risk of nurses being heavily burdened as a consequence of being involved in this practice (122).

End-of-life decisions in children

Nurses who work in paediatric intensive care units (PICU) are likely to be confronted with possible life-shortening end-of-life decisions, and have a high level of involvement in those decisions, especially in carrying out the decision. They are not likely to initiate the discussion about a possible end-of-life decision and are in only half of the cases involved in the physician's decision-making.
These findings are in congruence with other research findings (123-126). Although the international literature and guidelines recommend more intensive interdisciplinary collaboration (123;127;128), this is not yet implemented in practice. We have to bear in mind that PICUs are often small units with a high collaboration rate with physicians from other departments. In intensive care units the consultation of colleague-physicians is very likely (129-131) and the end-of-life decisions are often discussed with the parents (132). These could be reasons that nurses are not always involved in decision-making. Besides, our study revealed that not all nurses wanted to be involved in the decision-making. Perhaps some nurses are more comfortable with the physician making the difficult decision that they just have to carry out. We can conclude that different nurses even working in identical small units may have different role fulfilments which can probably change depending on each unique situation. Notwithstanding the nurses' wish to be involved or not in the decision-making (and most did want to be involved), in all cases, clear communication from the physician towards the nursing team is indispensable because nurses fulfil an important role in carrying out the decision. The lack of it is often experienced as a source of conflict within the team (133). During the performance, nurses mainly had a supportive role towards the child and the family (76%), and a preparatory role (65%). It seems that nurses feel they have responsibilities towards the child and the family (124;134), but also towards the physician. Their role sometimes even goes further in the actual implementation of the end-of-life decision. Also in the administering of life-ending drugs, the PICU nurses indicated that they implemented the action in presence of the physician (62%) and sometimes without his/her presence (31%). In the latter we even can assume that the nurses actually administer the life-ending drugs to the child.

In general, the involvement of PICU nurses seems to be similar to that of nurses who care for terminally ill patients in general whose treatment also involved an end-of-life decision, with the exception of the extensive role PICU nurses undertook during the performance. This is most likely to be the consequence of the particular characteristics of the setting which is mostly a very small scale unit with a highly technological environment. Nurses are continuously present and provide the intensive care of the terminally ill child who has very specific and high-level care needs.

Specification by health care setting

The most conspicuous differences between health care settings are that home care nurses see their role in end-of-life practices as less extensive and are involved less often in end-of-life practices, especially in the physician's decision-making process than are nurses working in an intramural setting; nurses who work in care homes are most often involved in the physician's decision-making; and hospital nurses are more willing to and more often do administer drugs with the explicit intention of ending a patient's life, which they also consider more often as a task nurses should be allowed to perform, than do home care nurses and nurses working in care homes. These differences very likely relate to characteristics of the care settings, the physician who is given the medical care, the nurses involved in the care, and to patients characteristics.

General practitioners mostly maintain a close, personal and long-standing relationship with their patients (78;105;135) and are used to operating in a more isolated context. The patients who die at home are mostly male patients, younger patients, more well educated patients and patients suffering from cancer with whom general practitioners often maintain good communication (e.g. the dying course of cancer patients is often more predictable than those who die from other causes (136) which might enhance the end-of-life decision-making of physicians). Nurses providing home care work autonomously in a minority of cases and in most cases in large agencies. In both, a structured interdisciplinary interface between physician and nurse is lacking. Both the general practitioner and the nurses who provide the care come to visit the patient once or several times a day/week and the communication between them is often written. These factors may all explain why nurses are less often involved in the physician's decision-making. Notwithstanding that these nurses also take up a more active role towards the patient and relatives (see chapter 8) and experience a good interpersonal contact with them, the lack of a structural discussion forum and the physicians' own personal contact with their patients probably explain why they see their own role as less extensive.

The general practitioner also provides the medical care of the patient in care homes. Care home patients are mostly older, have complex pathologies and co-morbidities and are very dependent on their daily caregiving team of which nurses are part. Nurses work autonomously and mostly in teams which consist predominantly – and sometimes solely – of nurses and some other paramedic carers in which nurses have the responsible function of the care of the resident. There is no permanency of physicians in care homes. Nurses are present 24 hours a day, know the patient very well, and are always available to the physician. For all those reasons the involvement of nurses in decision-making is easy to realize, and therefore occurs more.

Specialists and nurses in hospitals work together in teams in which an interdisciplinary discussion forum is integrated into the work structure. Discussions are regularly held in which clear assignment of tasks are made.

However, this does not automatically imply that nurses are always involved in the physician's decision-making, possibly because colleague physicians are also available. In hospitals the delegation of the decisions physicians make is common practice and evidently includes the administering of drugs, but clearly goes further, even to the administering of drugs explicitly intended to hasten the patient's death. The hierarchical relationship between physicians and nurses is most visible in hospitals. The work structure in hospitals, with both nurses and physicians available 24h a day, with physicians standing in an executive role, and nurses being technically skilled (78;137) may contribute to the willingness of nurses to perform the administering of drugs and may even mould their attitudes towards the nurse's role as possible administrator of drugs in cases of euthanasia. In a study performed in the Netherlands, a considerable number of specialists working in hospitals also thought that nurses should be allowed to administer the drugs in euthanasia, more than that physicians in care homes and general practitioners did (78). Further, we found that hospital nurses more often accept the practice of continuous deep sedation and are also more willing to administer the drugs in such practice than other nurses, probably as a consequence of having more experiences of it. In Belgium as in the Netherlands, continuous deep sedation occurs more often in hospital settings (50;56;112;138;139). Hospital nurses are likely to be more familiar with the practice, which could shape their attitudes towards it and lead to higher acceptance rates.

In conclusion, nurses working in different health care settings see their role in end-of-life practices differently and are also involved differently. Questions do remain as to whether the attitudes nurses hold towards their role determine the way they will act in end-of-life practices or whether the experience they gain through their work in a particular setting leads to the perception of another role in end-of-life decisions.

Implications and recommendations for practice and policy

Nurses have an important role in end-of-life care in general and in end-of-life decisions in particular. This can be deduced from different givens. First, general and specific legislation and professional codes point to the particular involvement of nurses in end-of-life care (33;94;140). Second, our study revealed that most nurses think that nurses should be involved in the whole process of end-of-life decisions, because of their central role in the care of the patient. And third, nurses do also have a role in those practices, some in communication with patients and/or relatives, some in the physician's decision-making, some in the performance, etc. Those aspects are therefore, among other things, the foundation for nurses making a large contribution to ensuring the quality of end-of-life care and decision-making. After all, what is to be considered of the utmost importance for healthcare policy is that all patients should be guaranteed the highest quality of end-of-life care. Every dying person should have the right to expert medical and nursing care in the framework of dignified integral care (141).

Influence of nurses' attitudes on practice

Although we did not study the particular influence of attitudes on practice, the following implications can be made. Nurses are the largest group of health care professionals providing care to patients and their relatives and are in the centre of the practice. Their high acceptance rate of end-of-life practices may influence their incidence. Nurses maintain close contact with the patient and his/her relatives who regularly communicate with nurses about such decisions (see chapters 7 & 8). Nurses who are averse to certain life-shortening end-of-life decisions, can influence the decisions patient and/or relatives make (85). Nurses can also have a considerable effect on physicians; they often have a steering function towards possible decisions. Physicians, especially in hospitals or in care homes, often have to turn to nurses because nurses are in a position to observe the patient at regular intervals and also maintain other, more social, contact (85). Nurses' attitudes and opinions towards end-of-life practices may influence the physician's decision-making and may be very determined in the end-of-life care that the patient further receive.

As most nurses agree with the different end-of-life practices, this also means that nurses as a group represent a shared opinion, making cooperation and communication between them more feasible. As well as cooperating with their nurse colleagues, nurses also have to cooperate with physicians who have similar acceptance rates (37). This may benefit good cooperation and optimal communication among and between the professional groups.

End-of-life decision-making and collaboration

Given the wish of nurses to be involved in end-of-life decision-making (chapters 2 & 3), their actual (and limited) involvement in the physician's decision-making (chapters 5 to 8), their specific expertise and qualifications, as mentioned above, and the evidence that close interdisciplinary collaboration is ethically desirable

and improves the quality of care (26;142;143), we recommend that nurses should be more often involved in end-of-life decision-making. The responsibility for making end-of-life decisions should remain with the physician, but in coming to that decision the nursing perspective should also be included. Besides, systematic consultation and involvement of nurses can be a kind of training and evaluation of decision-making for physicians (144). In order to come to a more considered decision-making and to real cooperation between both groups, the responsibility is laid within both professions in which physicians should see the value of the nurses' contribution to their decision-making and nurses being more assertive to claim this contribution. More attention should be given to it in national and institutional guidelines, in vocational and specialized education, in training modules and lectures, etc.

In home care, the involvement of nurses in decision-making seems to be even more problematic. Nurses are only consulted in a limited way, they think less often that they have to be involved in decision-making and evaluate the cooperation with the physician less often as positive than their colleagues in the intramural setting. Improved collaboration is more challenging due to the independence of the general practitioner (and his/her individuality and willingness to cooperate with nurses, as they are used to working alone) and the lack of a structural interface. Additional measures should be taken to involve nurses in decision-making and to create a platform in which adequate reciprocal information about the wishes and needs of the patient, the current state of affairs, questions, doubts and frustrations, etc could be exchanged. Initiatives can be taken by the large home care agencies, in cooperation with united local groups of general practitioners, to install a regular and structural interdisciplinary discussion forum with the caregivers involved, after the example of the multidisciplinary palliative home care teams that are acquainted with such team discussion.

Towards a clear viewpoint about responsibilities & roles in euthanasia
Euthanasia is a distinct end-of-life practice as there is a law dealing with the issue and therefore providing the physician and other health care professionals indications how to act. The law prescribes that the patient's request must be discussed with the nurses involved. Our study clearly demonstrate that this is far from perfect (chapter 5) and that this discussion merely implies that information about the patient's condition or wishes is being exchanged (chapter 7). We also demonstrate that nurses are highly involved in the performance of euthanasia, not only in preparatory activities (chapter 7), but also in the actual administering of the drugs (chapters 5 to 7). The law for this matter provides no clear-cut information about what is allowed or not, except that the physician must perform the euthanasia. In normal medical practice nurses could perform all the preparatory activities, but euthanasia does not fall under this practice. An article in the law also states that nobody can be forced to cooperate in the euthanasia performance, which presumes that other persons that the physician may cooperate, but the content of those acts is not clear. The ignorance is therefore understandable. We can conclude from our findings that clinical practice is not

always in accordance with the law. It can be questioned whether the present regulations are the best option for practicable and good end-of-life care (145). Nurses are finding themselves in a precarious legal position and their involvement in euthanasia can even damage the nursing profession (which is characterized by the preservation, the improvement and the restoration of the health of healthy and sick persons and groups (94)). However, we have to be aware that nurses work in a particular system of labour relations, in which they are in a hierarchical relationship with the physician, which places them sometimes in conflicting positions. Notwithstanding this, they do have the right to make conscientious objections to euthanasia and may withhold themselves from further care, as stated in the law. The deontological code of nursing also explicitly states that nurses have the duty to reject an order from a superior when it does not fall within their expertise (140). Questions, however, remain about whether nurses are fully aware of the tasks they may or may not legally perform.

As the prescription that the euthanasia request has to be discussed with nurses is not always followed and as it is not really clear what is actually meant with discussed, more transparency is recommended, for example that an actual discussion about the patient's request must be organized. This can be further concretized that the nursing team makes a report about that discussion which is added to the patient's record, but has no legal binding. Euthanasia should remain a physician-patient affair in which the physician holds final responsibility and patient's wishes should be respected. Next, it is highly recommended that vagueness and uncertainties about nurses' responsibilities in the performance are clarified. It should be made clear what nurses are allowed to perform.

Some people propose the amendment of the euthanasia law concerning the role of nurses in order to enhance and safeguard their legal status. In 2007, a professional nursing organization drew up a proposal to amend the law in which it is explicitly stated that the nurse may receive the drugs from the pharmacist and that some preparatory acts may be performed by nurses, to be determined in a royal resolution. This proposal has had no consequences (146). New initiatives on the political level are currently being taken but such an amendment is not supported by many people who state that it will make current practice more complex. In the first place nurses should be aware of the content of the current law. There seems to be evidence that a considerable group of nurses are not aware as to which actions they are allowed to perform in cases of euthanasia (chapter 3). Secondly, guidelines could refine and give further interpretations of how the law should be understood, in particular in the scope of this dissertation, about the responsibilities of all caregivers involved. The intention of guidelines is not to treat euthanasia in a business-like or technical manner, but to assist all those involved in providing optimal care for patients and relatives (13). The use of guidelines would create transparency and clarity, define the responsibilities of the different health care providers, may help to build consensus, can avoid conflicts among caregivers, can improve the consistency of care regardless who delivers the care, can give the health care providers something to hold on to, might avoid wrong interpretations, and serves as a

cornerstone for quality (26;141;147;148). A deficit in communication within the healthcare team, especially between physicians and nursing staff, can have far-reaching consequences, for example legal complaints (149).

In the development of a guideline, importance should be placed upon a correct interpretation of the law and the avoidance of personal beliefs in interpreting it. In 2004, initiatives were taken in Flanders to create a clinical practice guideline in cases of euthanasia by Caritas Flanders, a Christian inspired organization, which was sent to their affiliated institutions. This guideline makes explicit how medical and nursing expertise could effectively be employed in the interdisciplinary care context (141). Although such initiatives should be encourage, a national guideline that sticks closely to the law, with nationwide coverage such as in the Netherlands, seems to be more appropriate. There, a national guideline for cooperation between physicians, nurses and other carers in euthanasia was developed in 2006 (150). In the guideline, it is clear that the involvement of nurses is very important and that their involvement in decision-making is desirable. Concerning preparatory and administration acts, there is a rule of thumb for the demarcation between the two. The nurse is not allowed to perform actions that lead directly to the ending of the patient's life; in other words there is still the physician who must take the essential action to realize the life-ending (150).

Not only the making of a guideline is important, but also the implementation in practice. In the example of the Netherlands, a study performed among nurses who have experience with euthanasia showed that most of them had no opinion about the national euthanasia guideline (86%), mostly because they have actually never have studied it (58%), and even sometimes because they never have heard of it (28%). One fourth of nurses also indicated that they were not aware of the presence of an institutional guideline. More than half also stated that they had a need for extra training, mostly about legislation and rules and about the position of nurses (81). It is of no use that a guideline exists if it is not fully implemented in practice, something which could be attained by education and training. Initiatives like the LEIF-nurses (Life End Information Forum), which has been installed since 2006, contribute to this knowledge. Nurses are being taught about legal requirements of the law, communication in euthanasia and other end-of-life decisions, nurses' roles, etc.

PICU nurses need more guidance too

As PICU nurses have an extensive role in the performance of end-of-life decisions that could precede a child's death, mostly want to be involved in decision-making, and have clear attitudes about the practice (chapter 4), their opinions, experiences and involvement should not be ignored, not only in discussions held publicly on the acceptance or refusal of intentional life-ending acts among terminally ill children, but also in discussions held in the PICU. For the latter, more intensive interdisciplinary collaboration is recommended (123;127;128), which could be easily realised by the presence of all health care providers in such units. This kind of collaboration can be successfully implemented in a PICU, and

will enhance communication and will contribute to end-of-life decision-making for the child and their family (128). Further, nurses' extensive role in the performance should be discussed and, especially when decisions are made that do not fall under normal medical and nursing behaviour, nurses should be aware that they have the right to refuse any further cooperation. Clear agreements should be made in order to prevent the moral distress that PICU nurses regularly experience (151). For realising these recommendations, the different PICUs could work together and create a protocol for guidance in end-of-life decisions. In the Netherlands, such protocol exists, the Groniger protocol, which not only increased public openness about the use of life ending drugs, but, more importantly in light of this dissertation, is likely to contribute towards guaranteeing careful decision-making. Consultation with others about the diagnosis and prognosis and about the decision to end the child's life by the administering of drugs is highly recommended (152). In Belgium, the administering of drugs explicitly intended to hasten death is illegal, but clearly occurring and considered by physicians and nurses as inevitable (61). Any guidance on life-ending and the role of the different health care providers, is lacking in Belgium and would not only contribute to the physician's good practice, but also to good practice for nurses. Those nurses also clearly indicated that public initiatives should be taken to allow life-ending among children. The legal vacuum that currently exists may hamper quality end-of-life care and place all healthcare professionals involved in it in an uncertain legal position.

Towards a clear framework of different end-of-life decisions

The framework about different end-of-life decisions should be clear for nurses. They should be able to distinguish between different far-reaching practices, such as given drugs explicitly intended to end life and aggressive pain and symptom alleviation. As nurses are frequently involved in administering drugs explicitly intended to hasten death, and in particular in those cases which involves opioids, and as they are also not averse to it, we have to recognize that it seems to be something that is considered as normal medical and nursing practice. We have to consider that perhaps not all nurses see any problem in administering for example morphine even if it is clearly intended to hasten the patient's death. However, it should be made clear that they are acting beyond their legal and professional nursing standards and are finding themselves in a legal vacuum. In personal communication with nurses, they indicated that increasing morphine with the intention to hasten the patient's death and not the pain and/or symptoms, is not euthanasia, while it is legally seen as "euthanasia" when it is done on the patient's explicit request and legally seen as "murder" when that request is lacking. We recommend that nurses should be clearly informed about possible actions near the end of life and their associated consequences. Also the physicians should be aware of the position they put nurses in when ordering the increase of drugs with the intention to hasten death.

Special concern for continuous deep sedation

Nurses have a lot of experience with the alleviation of pain and suffering of patients who are at their end of life. Continuous deep sedation is also a form of

pain and symptom alleviation, but it is found that the practice is not always clear and for many nurses there seems to be a small overlap between continuous deep sedation and intentionally life-ending. This could be the result of a poor communication between physicians and nurses whereby physicians do not always inform nurses about the purpose and the estimated effect of the sedation. However, it could equally be that physicians sometimes perform continuous deep sedation with the explicit intention to hasten death (56;112;139). It seems to be very important to distinguish the practice of continuous deep sedation from the normal pain and symptom alleviation and the intentionally life-ending. More discussion within the nursing profession and between different disciplines – medical, nursing, legal, and ethical perspectives – should be hold. Those discussions can give the initial impetus to the creation of guidelines, in which among other things, indications could be made as to where nurses can contribute to the carefulness of the practice and where their contribution to decision-making can not be ignored. The Dutch national guideline on palliative sedation sets a good example for others, and is also proven to have contributed to a careful practice (153). However, not only a guideline is needed; training and knowledge dissemination with specific focus points for each setting are equally necessary (154). Our study showed that different health care settings involved different kinds of patients receiving continuous deep sedation, nurses being differently involved and rating their involvement differently.

Improved education on end-of-life practices in general
There is a universal need for education in end-of-life care in general and in end-of-life practices in particular (13;155;156). Learning about palliative care, possible life-shortening end-of-life decisions and ethics at the end of life should be realized in the nurses' basic education as has been recommended internationally by the European Association of Palliative Care (157) and nationally by the Flemish Federation Palliative Care. We have to bear in mind that not only nurses who are specialized in palliative care are being confronted with end-of-life practices. Furthermore, better education in palliative care would contribute to a profound understanding of management of symptoms, and could avoid ambiguity of practices in which large doses of drugs are given without knowing what effect they have on the hastening of the patient's death.

Next, education in communication skills seems appropriate. Enhancing the competence to communicate with other health care professionals, but also with the patient and relatives deserves more attention in vocational and post-graduate education. Special attention should be given to the empowerment of nurses in their work relations. Nurses have the right to refuse actions that are legally not theirs to perform. Better communication skills and the cooperation with other professional groups should, however, not only be implemented in nursing education, but also in medical education. It would be unbalanced to lay down all the responsibility in the nursing profession, while involvement in good communication also requires the willingness and competence of physicians. Besides, physicians give instructions to nurses and they should also be aware of the boundaries of those delegations.

In conclusion, to improve the quality of care at the end of life, it must be ensured that vocational and post-graduate education and training of healthcare professionals includes sufficient time devoted to palliative care as well as to the different ethical, legal, and professional aspects of all medical end-of-life decisions. Important items that must be addressed in such education include among others effective pain- and symptom management, pharmacological knowledge, communication skills and multidisciplinary cooperation (157).

Involvement of nurses in public debates of end-of-life practices
As patient advocates, experts and professionals who spend a great deal of time with dying patients, it is surprising that nurses have been on the sideline in discussions surrounding end-of-life practices (15;47;53). Nurses, who are the largest group of health care professionals, are intensively involved in the care which obviously will leave a mark on how this care is delivered and understood. It is therefore recommended that the nursing profession should be involved in public debates about end-of-life practices and that their voices are heard, notwithstanding which debates are being held. The nursing profession has a task to participate in the development of quality of public health care (140). It should also be opportune to have more people with a nursing background in policy, which could be realized by more nurses having completed master education. Further, debates are currently being held on the permissibility of euthanasia among children and among patients suffering from dementia. Discussions should, however, not be limited to euthanasia, but should expand to all different kinds of end-of-life practices, such as continuous deep sedation and other end-of-life practices that can also be perceived as problematic and can induce discussions and moral objections, etc as much euthanasia can.

Recommendations for further research

Improving clinical practice starts with good monitoring of the current situation, and nurses are in a good position to do so. They seem to be the intermediaries between the patient and relatives on the one hand and the physician on the other (chapters 7 & 8). They also have their particular expertise in observing, recognizing and documenting the state of the patient's condition (94). Perceptions by nursing staff may be a reliable indicator of the quality of medical end-of-life decision-making.

In our study, we could not determine whether nurses also accept the practice of euthanasia for example for patients who suffer from dementia or were tired of living without any serious or incurable disorder. We also did not take all relevant clinical and personal circumstances into account though they have been proved to play a role in the constitution of attitudes towards euthanasia and other end-of-life practices (10-12). In our study, nurses also regularly commented at the end of the questionnaire that they would accept life-ending acts on certain conditions, such as if the relatives agree with the practice, all legal conditions were being met, all members of the health care team were in accordance, etc. Large scale studies questioning nurses about their attitudes that take contextual elements into account are recommended in order to provide more nuances. In those kinds of studies, the exploration of the motivations of nurses in their conception and differentiation of possible life-ending acts is also important. Next, we did not relate the attitudes nurses hold to their actual involvement in end-of-life practices. Further analyses should be made to understand how attitudes are related to the role nurses actually had in end-of-life practices. Third, as physicians and nurses work closely together in the care of the terminally ill patient, it is of utmost importance that both groups are asked about their attitudes towards the practice, but also about their attitudes towards the role of the different professional groups. It is not only important to study how they view the role of their own professional group, but also that of the other. This might bring out many important aspects, of nurses' involvement in decision-making, and of more concrete points such as do nurses prefer physicians to make end-of-life decisions together with them and are physicians also willing to involve nurses in that way. As physicians are the responsible parties in making such decisions, their opinions about nurses' role in end-of-life practices should not be ignored.

As further research should focus on how the two largest professional groups of health care providers see their role in end-of-life practices, this should also be done for their involvement in those practices. A comparison of the perceptions of physicians and nurses in actual end-of-life practices can provide further insights into the reasons why physicians and nurses entertain other perceptions, other role conceptions, etc. Finally, physicians have been asked about the involvement of nurses in the decision-making and performance of euthanasia and other end-of-life practices, but only in a limited way. More research is needed on the reasons why physicians involve nurses or not, and on identifying the kind of involvement that is perceived as necessary to provide high quality of end-of-life

care for all kinds of patients. This kind of information is needed to create clear policy recommendations and the completion of guidelines.

The formulation of quality indicators in which the influence of nursing involvement on quality of end-of-life decision-making can be measured, is another recommendation for further research. It is important to know how nurses can contribute to patients receiving high quality end-of-life care. As such, quality indicators should firstly be developed wherein nurses can make a contribution as they are experts in caring for the patient and have a profound knowledge about the practice. In a second stage, intervention studies, such as randomised control trials, could be helpful to study the impact of nurses' involvement on end-of-life decision-making and quality end-of-life care.

From our studies, we found some social inequalities in the involvement of nurses in end-of-life practices (e.g. more nursing involvement in lower educated patients, in older patients). There were also marked differences between groups of nurses, and especially between different health care settings, wherein physicians and nurses work differently, different kinds of patients are being cared for, and with patients possibly having other expectations towards their treating physician and caring nurses. Future research about possible care pathways with particular emphasis on the involvement of health care professionals and including different kinds of patients, could result in a better provision of end-of-life care and decision-making.

Finally, using the same methodologies, and taking into account the legal, social, and professional characteristics of countries, international comparative research should be performed. Nurses all over the world are involved in euthanasia and end-of-life practices. Comparisons can provide important insights into the different roles nurses fulfil in such practices.

References

(1) Georges JJ, Grypdonck M. Moral problems experienced by nurses when caring for terminally ill people: a literature review. Nurs Ethics 2002; 9(2):155-178.
(2) De Bal N, Dierckx de Casterlé B, De Beer T, Gastmans C. Involvement of nurses in caring for patients requesting euthanasia in Flanders (Belgium): A qualitative study. Int J Nurs Stud 2006.
(3) Asai A, Ohnishi M, Nagata SK, Tanida N, Yamazaki Y. Doctors' and nurses' attitudes towards and experiences of voluntary euthanasia: survey of members of the Japanese Association of Palliative Medicine. J Med Ethics 2001; 27(5):324-330.
(4) Tanida N, Asai A, Ohnishi M et al. Voluntary active euthanasia and the nurse: a comparison of Japanese and Australian nurses. Nurs Ethics 2002; 9(3):313-322.
(5) Ganzini L, Harvath TA, Jackson A, Goy ER, Miller LL, Delorit MA. Experiences of Oregon nurses and social workers with hospice patients who requested assistance with suicide. N Engl J Med 2002; 347(8):582-588.
(6) Asch DA. The role of critical care nurses in euthanasia and assisted suicide. N Engl J Med 1996; 334(21):1374-1379.
(7) Kumas G, Öztunç G, Alparslan Z. Intensive care unit nurses' opinions about euthanasia. Nurs Ethics 2007; 14(5):637-650.
(8) Matzo ML, Emanual EJ. Oncology nurses' practices of assisted suicide and patient-requested euthanasia. Oncol Nurs Forum 1997; 24(10):1725-1732.
(9) Young A, Volker D, Rieger PT, Thorpe DM. Oncology nurses' attitudes regarding voluntary, physician-assisted dying for competent, terminally ill patients. Oncol Nurs Forum 1993; 20(3):445-451.
(10) Frileux S, Lelievre C, Munoz Sastre MT, Mullet E, Sorum PC. When is physician assisted suicide or euthanasia acceptable? J Med Ethics 2003; 29(6):330-336.
(11) Teisseyre N, Mullet E, Sorum PC. Under what conditions is euthanasia acceptable to lay people and health professionals? Soc Sci Med 2005; 60(2):357-368.
(12) Hagelin J, Nilstun T, Hau J, Carlsson HE. Surveys on attitudes towards legalisation of euthanasia: importance of question phrasing. J Med Ethics 2004; 30(6):521-523.
(13) Berghs M, Dierckx de Casterlé B, Gastmans C. The complexity of nurses' attitudes toward euthanasia: a review of the literature. J Med Ethics 2005; 31(8):441-446.
(14) De Bal N, Gastmans C, Dierckx de Casterlé B. Nurses' involvement in the care of patients requesting euthanasia: a review of the literature. Int J Nurs Stud 2008; 45(4):626-644.
(15) Verpoort C, Gastmans C, De Bal N, Dierckx de Casterlé B. Nurses' attitudes to euthanasia: a review of the literature. Nurs Ethics 2004; 11(4):349-365.
(16) Aranda S, O'Conner M. Euthanasia, nursing and care of the dying: rethinking Kuhse and Singer. Aust Nurs J 1995; 3(2):18-21.
(17) Van den Block L, Deschepper R, Bossuyt N et al. Care for patients in the last months of life: the Belgian Sentinel Network Monitoring End-of-Life Care study. Arch Intern Med 2008; 168(16):1747-1754.
(18) McInerney F, Seibold C. Nurses' definitions of and attitudes towards euthanasia. J Adv Nurs 1995; 22(1):171-182.
(19) Davis AJ, Davidson B, Hirschfield M et al. An international perspective of active euthanasia: attitudes of nurses in seven countries. Int J Nurs Stud 1993; 30(4):301-310.
(20) van der Maas PJ, van der Wal G, Haverkate I et al. Euthanasia, physician-assisted suicide, and other medical practices involving the end of life in the Netherlands, 1990-1995. N Engl J Med 1996; 335(22):1699-1705.
(21) Kuhse H, Singer P, Baume P, Clark M, Rickard M. End-of-life decisions in Australian medical practice. Med J Aust 1997; 166(4):191-196.
(22) Deliens L, Mortier F, Bilsen J et al. End-of-life decisions in medical practice in Flanders, Belgium: a nationwide survey. Lancet 2000; 356(9244):1806-1811.
(23) van der Heide A, Deliens L, Faisst K et al. End-of-life decision-making in six European countries: descriptive study. Lancet 2003; 362(9381):345-350.
(24) van der Heide A, Onwuteaka-Philipsen BD, Rurup ML et al. End-of-life practices in the Netherlands under the Euthanasia Act. N Engl J Med 2007; 356(19):1957-1965.

(25) Chambaere K, Bilsen J, Cohen J et al. A post-mortem survey on end-of-life decisions using a representative sample of death certificates in Flanders, Belgium: research protocol. BMC Public Health 2008; 8:299.
(26) Ferrand E, Lemaire F, Regnier B et al. Discrepancies between perceptions by physicians and nursing staff of intensive care unit end-of-life decisions. Am J Respir Crit Care Med 2003; 167(10):1310-1315.
(27) Thomas EJ, Sexton JB, Helmreich RL. Discrepant attitudes about teamwork among critical care nurses and physicians. Crit Care Med 2003; 31(3):956-959.
(28) Kuuppelomaki M. Attitudes of cancer patients, their family members and health professionals toward active euthanasia. Eur J Cancer Care (Engl) 2000; 9(1):16-21.
(29) Kuhse H, Singer P. Voluntary euthanasia and the nurse: an Australian survey. Int J Nurs Stud 1993; 30(4):311-322.
(30) Matzo ML, Schwarz JK. In their own words: oncology nurses respond to patient requests for assisted suicide and euthanasia. Appl Nurs Res 2001; 14(2):64-71.
(31) Verpoort C, Gastmans C, Dierckx de Casterlé B. Palliative care nurses' views on euthanasia. J Adv Nurs 2004; 47(6):592-600.
(32) Belgian Ministry of Justice. Wet betreffende de rechten van de patiënt 22 augustus 2002 (Law concerning patient rights August 22, 2002). 2002022737. 26-9-000
(33) Belgian Ministry of Justice. Wet betreffende palliatieve zorg 14 juni 2002 (Law on palliative care June 14, 2002). 2002022868. 26-10-2002.
(34) Belgian Ministry of Justice. Wet betreffende euthanasie 28 mei 2002 (Law on euthanasia May 28, 2002). 2002009590. 22-6-2002.
(35) Bilsen J, Cohen J, Chambaere K et al. Medical end-of-life practices under the euthanasia law in Belgium. N Engl J Med 2009; 361(11):1119-1121.
(36) Miccinesi G, Fischer S, Paci E et al. Physicians' attitudes towards end-of-life decisions: a comparison between seven countries. Soc Sci Med 2005; 60(9):1961-1974.
(37) Smets T, Cohen J, Bilsen J, Van Wesemael Y, Rurup ML, Deliens L. Attitudes and experiences of Belgian physicians regarding euthanasia practice and the euthanasia law. Soc Sci Med 2010; In review.
(38) Smets T, Bilsen J, Cohen J, Rurup ML, Deliens L. Legal euthanasia in Belgium: characteristics of all reported euthanasia cases. Med Care 2010; 48(2):187-192.
(39) Addington-Hall JM, Karlsen S. A national survey of health professionals and volunteers working in voluntary hospice services in the UK. I. Attitudes to current issues affecting hospices and palliative care. Palliat Med 2005; 19(1):40-48.
(40) Asch DA, DeKay ML. Euthanasia among US critical care nurses. Practices, attitudes, and social and professional correlates. Med Care 1997; 35(9):890-900.
(41) Miller LL, Harvath TA, Ganzini L, Goy ER, Delorit MA, Jackson A. Attitudes and experiences of Oregon hospice nurses and social workers regarding assisted suicide. Palliat Med 2004; 18(8):685-691.
(42) Cartwright CM, Williams GM, Parker MH, Steinberg MA. Does being against euthanasia legislation equate to being anti-euthanasia? Intern Med J 2006; 36(4):256-259.
(43) Kitchener BA. Nurse characteristics and attitudes to active voluntary euthanasia: a survey in the Australian Capital Territory. J Adv Nurs 1998; 28(1):70-76.
(44) Bendiane MK, Galinier A, Favre R et al. French district nurses' opinions towards euthanasia, involvement in end-of-life care and nurse patient relationship: a national phone survey. J Med Ethics 2007; 33(12):708-711.
(45) Bendiane MK, Bouhnik AD, Galinier A, Favre R, Obadia Y, Peretti-Watel P. French hospital nurses' opinion about euthanasia and physician-assisted suicide: a national phone survey. J Med Ethics 2009; 35(4):238-244.
(46) Cohen J, Marcoux I, Bilsen J, Deboosere P, van der Wal G, Deliens L. European public acceptance of euthanasia: socio-demographic and cultural factors associated with the acceptance of euthanasia in 33 European countries. Soc Sci Med 2006; 63(3):743-756.
(47) Broeckaert B. Belgium: towards a legal recognition of euthanasia. European Journal of Health Law 2001; 8(2):95-107.
(48) Gielen J, van den Branden S, van Iersel T, Broeckaert B. Flemish palliative care nurses' attitudes toward euthanasia: a quantitative study. Int J Palliat Nurs 2009; 15(10):488-497.

(49) Gastmans C, Lemiengre J, van der Wal G, Schotsmans P, Dierckx de Casterlé B. Prevalence and content of written ethics policies on euthanasia in Catholic healthcare institutions in Belgium (Flanders). Health Policy 2006; 76(2):169-178.
(50) Van den Block L, Deschepper R, Bilsen J, Bossuyt N, Van Casteren V, Deliens L. Euthanasia and other end of life decisions and care provided in final three months of life: nationwide retrospective study in Belgium. BMJ 2009; 339:b2772.
(51) Bernheim JL, Deschepper R, Distelmans W, Mullie A, Bilsen J, Deliens L. Development of palliative care and legalisation of euthanasia: antagonism or synergy? BMJ 2008; 336(7649):864-867.
(52) Guedj M, Gibert M, Maudet A, Munoz Sastre MT, Mullet E, Sorum PC. The acceptability of ending a patient's life. J Med Ethics 2005; 31(6):311-317.
(53) Denier Y, Dierckx de Casterlé B, De Bal N, Gastmans C. Involvement of nurses in the euthanasia care process in Flanders (Belgium): an exploration of two perspectives. J Pal Care 2010; 25(4):264-274.
(54) Lewis P. The empirical slippery slope from voluntary to non-voluntary euthanasia. J Law Med Ethics 2007; 35(1):197-210.
(55) Seymour JE, Janssens R, Broeckaert B. Relieving suffering at the end of life: practitioners' perspectives on palliative sedation from three European countries. Soc Sci Med 2007; 64(8):1679-1691.
(56) Rietjens J, van Delden JJ, Onwuteaka-Philipsen B, Buiting H, van der Maas PJ, van der Heide A. Continuous deep sedation for patients nearing death in the Netherlands: descriptive study. BMJ 2008; 336(7648):810-813.
(57) Bilsen J, Vander Stichele R, Broeckaert B, Mortier F, Deliens L. Changes in medical end-of-life practices during the legalization process of euthanasia in Belgium. Soc Sci Med 2007; 65(4):803-808.
(58) Gielen J, van den Branden S, Broeckaert B. Religion and nurses' attitudes to euthanasia and physician assisted suicide. Nurs Ethics 2009; 16(3):303-318.
(59) Sacred Congregation for the Doctrine of the Faith. Declaration on Euthanasia. Vaticaan . 5-5-1980.
(60) Cohen J, van Delden JJ, Mortier F et al. Influence of physicians' life stances on attitudes to end-of-life decisions and actual end-of-life decision-making in six countries. J Med Ethics 2008; 34(4):247-253.
(61) Provoost V, Cools F, Mortier F et al. Medical end-of-life decisions in neonates and infants in Flanders. Lancet 2005; 365(9467):1315-1320.
(62) Solomon MZ, Sellers DE, Heller KS et al. New and lingering controversies in pediatric end-of-life care. Pediatrics 2005; 116(4):872-883.
(63) Burns JP, Mitchell C. Is there any consensus about end-of-life care in pediatrics? Arch Pediatr Adolesc Med 2005; 159(9):889-891.
(64) Burns JP, Mitchell C, Outwater KM et al. End-of-life care in the pediatric intensive care unit after the forgoing of life-sustaining treatment. Crit Care Med 2000; 28(8):3060-3066.
(65) Keenan HT, Diekema DS, O'Rourke PP, Cummings P, Woodrum DE. Attitudes toward limitation of support in a pediatric intensive care unit. Crit Care Med 2000; 28(5):1590-1594.
(66) McMillen RE. End of life decisions: nurses perceptions, feelings and experiences. Intensive Crit Care Nurs 2008; 24(4):251-259.
(67) Dierckx de Casterlé B, Verpoort C, De BN, Gastmans C. Nurses' views on their involvement in euthanasia: a qualitative study in Flanders (Belgium). J Med Ethics 2006; 32(4):187-192.
(68) de Veer AJ, Francke AL, Poortvliet EP. Nurses' involvement in end-of-life decisions. Cancer Nurs 2008; 31(3):222-228.
(69) Thacker KS. Nurses' advocacy behaviors in end-of-life nursing care. Nurs Ethics 2008; 15(2):174-185.
(70) Cartwright C, Onwuteaka-Philipsen BD, Williams G et al. Physician discussions with terminally ill patients: a cross-national comparison. Palliat Med 2007; 21(4):295-303.
(71) Michiels E, Deschepper R, Bilsen J, Mortier F, Deliens L. Information disclosure to terminally ill patients and their relatives: self-reported practice of Belgian clinical specialists and general practitioners. Palliat Med 2009; 23(4):345-353.

(72) Steinhauser KE, Christakis NA, Clipp EC, McNeilly M, McIntyre L, Tulsky JA. Factors considered important at the end of life by patients, family, physicians, and other care providers. JAMA 2000; 284(19):2476-2482.
(73) Nolan MT, Mock V. A conceptual framework for end-of-life care: a reconsideration of factors influencing the integrity of the human person. J Prof Nurs 2004; 20(6):351-360.
(74) Dunne K. Effective communication in palliative care. Nurs Stand 2005; 20(13):57-64.
(75) Emanuel EJ, Emanuel LL. The promise of a good death. Lancet 1998; 351 Suppl 2:SII21-SII29.
(76) van Bruchem-van de Scheur GG, van der Arend AJ, Huijer Abu-Saad H, Spreeuwenberg C, van Wijmen FC, Ter Meulen RH. The role of nurses in euthanasia and physician-assisted suicide in The Netherlands. J Med Ethics 2008; 34(4):254-258.
(77) van Bruchem-van de Scheur GG, van der Arend AJ, Huijer Abu-Saad H, Spreeuwenberg C, van Wijmen FC, Ter Meulen RH. The role of nurses in euthanasia and physician-assisted suicide in The Netherlands. J Med Ethics 2008; 34(4):254-258.
(78) Muller MT, Pijnenborg L, Onwuteaka-Philipsen BD, van der Wal G, van Eijk JT. The role of the nurse in active euthanasia and physician-assisted suicide. J Adv Nurs 1997; 26(2):424-430.
(79) Cartwright C, Steinberg M, Williams G, Najman J, Williams G. Issues of death and dying: the perspective of critical care nurses. Aust Crit Care 1997; 10(3):81-87.
(80) Bourdieu P, Passeron JC, Chamboredon JC. Le metier de sociologue. Paris, France: Mouton, Bordas, 1968.
(81) van Bruchem-van de Scheur A, van der Arend A, Spreeuwenberg C, van Wijmen F, ter Meulen R. De rol van verpleegkundigen bij medische beslissingen aan het levenseinde: verslag van een landelijk onderzoek naar betrokkenheid en praktijken. De Tijdstroom, Utrecht, 2004.
(82) Cook DJ, Guyatt GH, Jaeschke R et al. Determinants in Canadian health care workers of the decision to withdraw life support from the critically ill. Canadian Critical Care Trials Group. JAMA 1995; 273(9):703-708.
(83) Rocker GM, Cook DJ, O'callaghan CJ et al. Canadian nurses' and respiratory therapists' perspectives on withdrawal of life support in the intensive care unit. J Crit Care 2005; 20(1):59-65.
(84) Ferrell B, Virani R, Grant M, Coyne P, Uman G. Beyond the Supreme Court decision: nursing perspectives on end-of-life care. Oncol Nurs Forum 2000; 27(3):445-455.
(85) The A. 'Vanavond om 8 uur...': Verpleegkundige dilemma's bij euthanasie en andere medische beslissingen rond het levenseinde. 1997. Houten, Bohn Stafleu Van Loghum.
(86) DeKeyser Ganz F, Musgrave CF. Israeli critical care nurses' attitudes toward physician-assisted dying. Heart Lung 2006; 35(6):412-422.
(87) Dawe U, Verhoef MJ, Page SA. Treatment refusal: the beliefs and experiences of Alberta nurses. Int J Nurs Stud 2002; 39(1):71-77.
(88) Breier-Mackie S. Patient autonomy and medical paternity: can nurses help doctors to listen to patients? Nurs Ethics 2001; 8(6):510-521.
(89) Gastmans C, Lemiengre J, Dierckx de Casterlé B. Role of nurses in institutional ethics policies on euthanasia. J Adv Nurs 2006; 54(1):53-61.
(90) Chambaere K, Bilsen J, Cohen J, Onwuteaka-Philipsen B, Mortier F, Deliens L. Physician-assisted dying in Belgian medical practice under the euthanasia act. A nationwide retrospective survey. Canadian Medical Association Journal 2010; Accepted.
(91) Frank RK. Shared decision making and its role in end of life care. Br J Nurs 2009; 18(10):612-618.
(92) Kilkus SP. Assertiveness among professional nurses. J Adv Nurs 1993; 18(8):1324-1330.
(93) Gastmans C, Dierckx de Casterlé B. Verpleegkundige excellentie: verpleegkunde tussen praktijk en ethiek. Maarssen: Elsevier gezondheidszorg, 2000.
(94) Belgian Ministry of Justice. Koninklijk besluit nr. 78 betreffende de uitoefening van de geneeskunst, de verpleegkunde, de paramedische beroepen en de geneeskundige commissies. 10-11-1967.
(95) Belgian Ministry of Justice. Wet tot aanvulling van de wet van 28 mei 2002 betreffende de euthanasie (Law supplementary to the law on euthanasia May 28, 2002). 2005/23052. 10-11-0005.
(96) Federale Controle- en Evaluatiecomissie voor euthanasie. Derde verslag Federale Controle en Evaluatiecommissie (2006-2007). 2008.

(97) Fohr SA. The double effect of pain medication: separating myth from reality. J Palliat Med 1998; 1(4):315-328.
(98) Bilsen J, Norup M, Deliens L et al. Drugs used to alleviate symptoms with life shortening as a possible side effect: end-of-life care in six European countries. J Pain Symptom Manage 2006; 31(2):111-121.
(99) Rurup ML, Borgsteede SD, van der Heide A, van der Maas PJ, Onwuteaka-Philipsen BD. Trends in the use of opioids at the end of life and the expected effects on hastening death. J Pain Symptom Manage 2009; 37(2):144-155.
(100) Ravenscroft AJ, Bell MD. 'End-of-life' decision making within intensive care–objective, consistent, defensible? J Med Ethics 2000; 26(6):435-440.
(101) Bendiane MK, Bouhnik AD, Favre R et al. Morphine prescription in end-of-life care and euthanasia: French home nurses' opinions. J Opioid Manag 2007; 3(1):21-26.
(102) Vander Stichele RH, Bilsen J, Bernheim J, Mortier F, Deliens L. Drugs used for euthanasia in Flanders, Belgium. Wiley InterScience 2003; 13:89-95.
(103) Sprung CL, Ledoux D, Bulow HH et al. Relieving suffering or intentionally hastening death: where do you draw the line? Crit Care Med 2008; 36(1):8-13.
(104) Peretti-Watel P, Bendiane MK, Moatti JP. Attitudes toward palliative care, conceptions of euthanasia and opinions about its legalization among French physicians. Soc Sci Med 2005; 60(8):1781-1793.
(105) van Bruchem-van de Scheur GG, van der Arend AJ, Spreeuwenberg C, Huijer Abu-Saad H, Ter Meulen RH. Euthanasia and physician-assisted suicide in the Dutch homecare sector: the role of the district nurse. J Adv Nurs 2007; 58(1):44-52.
(106) van de Scheur A, van der Arend A. The role of nurses in euthanasia: a Dutch study. Nurs Ethics 1998; 5(6):497-508.
(107) Rietjens JA, Bilsen J, Fischer S et al. Using drugs to end life without an explicit request of the patient. Death Stud 2007; 31(3):205-221.
(108) Delbeke E. Deschemerzone tussen levensbeëindiging en pijnbestrijding met mogelijk levensverkortend effect: proportionaliteit van de pijnmedicatie en het belang van transparantie. Tijdschrift voor gezondheidsrecht 2009; 10:4-15.
(109) Broeckaert B. Tretament decisions at the end of life. In: Payne S, Seymour J, Ingleton C, editors. Palliative care nursing: principles and evidence for practice. Berkshire, England: Open University Press, 2008.
(110) De Gendt C, Bilsen J, Mortier F, Vander Stichele R, Deliens L. End-of-life decision-making and terminal sedation among very old patients. Gerontology 2009; 55(1):99-105.
(111) Jansen-van der Weide MC, Onwuteaka-Philipsen BD, van der Wal G. Granted, undecided, withdrawn, and refused requests for euthanasia and physician-assisted suicide. Arch Intern Med 2005; 165(15):1698-1704.
(112) Rietjens JA, van der Heide A, Vrakking AM, Onwuteaka-Philipsen BD, van der Maas PJ, van der Wal G. Physician reports of terminal sedation without hydration or nutrition for patients nearing death in the Netherlands. Ann Intern Med 2004; 141(3):178-185.
(113) Morita T, Chinone Y, Ikenaga M et al. Efficacy and safety of palliative sedation therapy: a multicenter, prospective, observational study conducted on specialized palliative care units in Japan. J Pain Symptom Manage 2005; 30(4):320-328.
(114) Chiu TY, Hu WY, Lue BH, Cheng SY, Chen CY. Sedation for refractory symptoms of terminal cancer patients in Taiwan. J Pain Symptom Manage 2001; 21(6):467-472.
(115) Committee on National Guideline for Palliative Sedation RDMA. KNMG-guideline for palliative sedation. 2009. Utrecht, KNMG.
(116) Verkerk M, van Wijlick E, Legemaate J, de Graeff A. A national guideline for palliative sedation in the Netherlands. J Pain Symptom Manage 2007; 34(6):666-670.
(117) Rietjens JA, van Delden JJ, van der Heide A et al. Terminal sedation and euthanasia: a comparison of clinical practices. Arch Intern Med 2006; 166(7):749-753.
(118) Materstvedt LJ, Kaasa S. Euthanasia and physician-assisted suicide in Scandinavia–with a conceptual suggestion regarding international research in relation to the phenomena. Palliat Med 2002; 16(1):17-32.
(119) Materstvedt LJ, Bosshard G. Deep and continuous palliative sedation (terminal sedation): clinical-ethical and philosophical aspects. Lancet Oncol 2009; 10(6):622-627.
(120) Billings JA, Block SD. Slow euthanasia. J Palliat Care 1996; 12(4):21-30.

(121) Quill TE, Lo B, Brock DW. Palliative options of last resort: a comparison of voluntarily stopping eating and drinking, terminal sedation, physician-assisted suicide, and voluntary active euthanasia. JAMA 1997; 278(23):2099-2104.
(122) Morita T, Miyashita M, Kimura R, Adachi I, Shima Y. Emotional burden of nurses in palliative sedation therapy. Palliat Med 2004; 18(6):550-557.
(123) Burns JP, Rushton CH. End-of-life care in the pediatric intensive care unit: research review and recommendations. Crit Care Clin 2004; 20(3):467-485.
(124) Copnell B. Death in the pediatric ICU: caring for children and families at the end of life. Crit Care Nurs Clin North Am 2005; 17(4):349-360.
(125) Meyer EC, Burns JP, Griffith JL, Truog RD. Parental perspectives on end-of-life care in the pediatric intensive care unit. Crit Care Med 2002; 30(1):226-231.
(126) Devictor DJ, Nguyen DT. Forgoing life-sustaining treatments: how the decision is made in French pediatric intensive care units. Crit Care Med 2001; 29(7):1356-1359.
(127) Hilden JM, Emanuel EJ, Fairclough DL et al. Attitudes and practices among pediatric oncologists regarding end-of-life care: results of the 1998 American Society of Clinical Oncology survey. J Clin Oncol 2001; 19(1):205-212.
(128) Sluiter JK, Bos AP, Tol D, Calff M, Krijnen M, Frings-Dresen MH. Is staff well-being and communication enhanced by multidisciplinary work shift evaluations? Intensive Care Med 2005; 31(10):1409-1414.
(129) Vincent JL. Forgoing life support in western European intensive care units: the results of an ethical questionnaire. Crit Care Med 1999; 27(8):1626-1633.
(130) Ferrand E, Robert R, Ingrand P, Lemaire F. Withholding and withdrawal of life support in intensive-care units in France: a prospective survey. French LATAREA Group. Lancet 2001; 357(9249):9-14.
(131) Svantesson M, Sjokvist P, Thorsen H. End-of-life decisions in Swedish ICUs. How do physicians from the admitting department reason? Intensive Crit Care Nurs 2003; 19(4):241-251.
(132) Provoost V, Cools F, Deconinck P et al. Consultation of parents in actual end-of-life decision-making in neonates and infants. Eur J Pediatr 2006; 165(12):859-866.
(133) Studdert DM, Burns JP, Mello MM, Puopolo AL, Truog RD, Brennan TA. Nature of conflict in the care of pediatric intensive care patients with prolonged stay. Pediatrics 2003; 112(3 Pt 1):553-558.
(134) Groot-Bollujt W, Mourik M. Bereavement: role of the nurse in the care of terminally ill and dying children in the pediatric intensive care unit. Crit Care Med 1993; 21(9 Suppl):S391-S392.
(135) Bilsen JJ, Vander Stichele RH, Mortier F, Deliens L. Involvement of nurses in physician-assisted dying. J Adv Nurs 2004; 47(6):583-591.
(136) Van den Block L, Bilsen J, Deschepper R, Van Der Kelen G, Bernheim JL, Deliens L. End-of-life decisions among cancer patients compared with noncancer patients in Flanders, Belgium. J Clin Oncol 2006; 24(18):2842-2848.
(137) van Bruchem-van de Scheur GG, van der Arend AJ, Huijer Abu-Saad H, van Wijmen FC, Spreeuwenberg C, Ter Meulen RH. Euthanasia and assisted suicide in Dutch hospitals: the role of nurses. J Clin Nurs 2008; 17(12):1618-1626.
(138) Miccinesi G, Rietjens JA, Deliens L et al. Continuous deep sedation: physicians' experiences in six European countries. J Pain Symptom Manage 2006; 31(2):122-129.
(139) Chambaere K, Bilsen J, Cohen J et al. Continuous deep sedation until death in Belgium: a nationwide survey. Arch Intern Med 2010; 170(5):490-493.
(140) Algemene Unie van Verpleegkundigen in België. Deontologische code voor verpleegkundigen in België. Algemene Unie van Verpleegkundigen in België . 1-11-2004.
(141) Gastmans C, Van Neste F, Schotsmans P. Facing requests for euthanasia: a clinical practice guideline. J Med Ethics 2004; 30(2):212-217.
(142) Faber-Langendoen K, Karlawish JH. Should assisted suicide be only physician assisted? University of Pennsylvania Center for Bioethics Assisted Suicide Consensus Panel. Ann Intern Med 2000; 132(6):482-487.
(143) Connor SR, Egan KA, Kwilosz DM, Larson DG, Reese DJ. Interdisciplinary approaches to assisting with end-of-life care and decision making. American Behavioral Scientist 2002; 46(3):340-356.
(144) Cohen J. End-of-life decisions and place of death in Belgium and Europe. Vrije Universiteit Brussel, 2007.

(145) Bilsen J. End-of-life decisions in medical practice in Flanders, Belgium. Vrije Universiteit Brussel, 2005.
(146) Vandenberghe L. Wetsvoorstel tot wijziging van de wet van 28 mei 2002 betreffende de euthanasie. Belgische senaat 3-1835/1. 7-9-2002.
(147) Haverkate I, Muller MT, Cappetti M, Jonkers FJ, van der Wal G. Prevalence and content analysis of guidelines on handling requests for euthanasia or assisted suicide in Dutch nursing homes. Arch Intern Med 2000; 160(3):317-322.
(148) Woolf SH, Grol R, Hutchinson A, Eccles M, Grimshaw J. Clinical guidelines: potential benefits, limitations, and harms of clinical guidelines. BMJ 1999; 318(7182):527-530.
(149) Damas F, Damas P, Lamy M. Euthanasia: a law in Belgium? Intensive Care Med 2001; 27(10):1683.
(150) AVVV, NU'91, KNMG. Handreiking voor samenwerking artsen, verpleegkundigen en verzorgenden bij euthanasie. AVVV NU'91 KNMG . 2006.
(151) Mekechuk J. Moral distress in the pediatric intensive care unit: the impact on pediatric nurses. Int J Health Care Qual Assur Inc Leadersh Health Serv 2006; 19(4-5):i-vi.
(152) Verhagen E, Sauer PJ. The Groningen protocol–euthanasia in severely ill newborns. N Engl J Med 2005; 352(10):959-962.
(153) Braun TC, Hagen NA, Clark T. Development of a clinical practice guideline for palliative sedation. J Palliat Med 2003; 6(3):345-350.
(154) Rietjens J. Medical decision-making at the end of life: experiences and attitudes of physicians and the general public. University Medical Center Rotterdam, 2005.
(155) Paice JA, Ferrell BR, Coyle N, Coyne P, Callaway M. Global efforts to improve palliative care: the International End-of-Life Nursing Education Consortium Training Programme. J Adv Nurs 2008; 61(2):173-180.
(156) Paice JA, Ferrell BR, Virani R, Grant M, Malloy P, Rhome A. Graduate nursing education regarding end-of-life care. Nurs Outlook 2006; 54(1):46-52.
(157) E.A.P.C. Palliative Nurse Education: report of the EAPC task force. www.eapcnet.org . 1-9-2004.

SAMENVATTING VAN DE BELANGRIJKSTE BEVINDINGEN

Achtergrond

Verpleegkundigen, als de grootste groep van zorgverleners, zijn in belangrijke mate betrokken bij het verlenen van zorg aan het levenseinde van patiënten. Voor een aanzienlijke groep van die patiënten worden medische beslissingen genomen die hun levenseinde beïnvloeden en mogelijk een levensverkortend effect hebben. Het is echter niet geweten hoe Vlaamse verpleegkundigen staan tegenover dergelijke beslissingen, zo ook niet hoe ze hun rol daarbinnen zien, en hoe ze daadwerkelijk betrokken zijn.

Onderzoeksvragen

I. Attitudes van verpleegkundigen:
   1. Wat zijn de attitudes ten aanzien van euthanasie en andere medische beslissingen aan het levenseinde
      a. van verpleegkundigen die zorg dragen voor patiënten in het algemeen?
      b. van verpleegkundigen die zorg dragen voor terminaal zieke kinderen?
   2. Hoe zien verpleegkundigen hun rol binnen euthanasie en andere beslissingen aan het levenseinde?

II. Betrokkenheid van verpleegkundigen:
   3. Hoe vaak worden verpleegkundigen door een arts geconsulteerd in verschillende medische beslissingen aan het levenseinde?
   4. Hoe zijn verpleegkundigen die zorg dragen voor terminaal zieke kinderen betrokken in medische beslissingen aan het levenseinde?
   5. Hoe zijn verpleegkundigen betrokken in euthanasie en het toedienen van levensbeëindigende middelen zonder verzoek van de patiënt?
   6. Hoe beschouwen verpleegkundigen continue diepe sedatie en hoe zijn ze erin betrokken?

Methode

We gebruikten drie verschillende methodes om onze onderzoeksvragen te kunnen beantwoorden.

Nu-ELD studie

De Nu-ELD studie [**Nu**rses in **E**nd-of-**L**ife **D**ecisions studie] had als doel om op een representatieve manier verpleegkundigen te vragen naar hun attitudes en betrokkenheid in euthanasie en andere medische beslissingen aan het levenseinde. In een eerste fase van de studie werd een grote steekproef van geregistreerde verpleegkundigen (N=6000) gevraagd naar hun attitudes ten aanzien van levenseindebeslissingen, en ten aanzien van hun rol erbinnen. We hebben daartoe gebruik gemaakt van stellingen waarbij de verpleegkundigen op

een 5-puntenschaal moesten aangeven in welke mate zij akkoord gingen. Verschillende persoonlijke en werkgerelateerde vragen over de verpleegkundigen zijn in deze vragenlijst opgenomen. In deze studie werd ook gepeild of de verpleegkundigen in de afgelopen 12 maanden zorg gedragen heeft voor een patiënt bij wie een medische beslissing aan het levenseinde werd uitgevoerd. Dit bepaalde de inclusie voor de betrokkenheid studie. In die tweede fase werden verpleegkundigen gevraagd zich de meest recent overleden patiënt te herinneren voor wie ze zorg gedragen hadden en bij wie een beslissing aan het levenseinde uitgevoerd werd. Informatie werd gevraagd over de overleden patiënt, over de beslissingen die voor deze patiënt aan het levenseinde werden genomen en de betrokkenheid van de verpleegkundigen binnen de genomen beslissingen.

De data van deze studies werden aangewend om enerzijds de onderzoeksvragen betreffende de attitudes van verpleegkundigen die zorg dragen voor patiënten te beantwoorden (hoofdstuk 2 & 3). Anderzijds werden de data gebruikt om de onderzoeksvragen met betrekking tot de betrokkenheid van verpleegkundigen in euthanasie, levensbeëindiging zonder verzoek en continue diepe sedatie te beantwoorden (hoofdstuk 7 & 8).

Sterfgevallenstudie
In 1998, 2001 en 2007 werden drie sterfgevallenstudies uitgevoerd. In elk van deze studies werd een toevallige steekproef getrokken van alle officiële overlijdensstatistieken in Vlaanderen van patiënten die 1 jaar of ouder zijn waarvan de artsen die het overlijdensattest hebben ondertekend een vragenlijst over de medische beslissingen aan het levenseinde van de patiënt invulden. Secundaire analyses werden gemaakt betreffende de betrokkenheid van verpleegkundigen in de besluitvorming van de arts omtrent dergelijke levenseindebeslissingen en in de toediening van levensbeëindigende middelen (hoofdstuk 5 & 6).

PIC-Nu studie
De PIC-Nu studie [**P**ediatric **I**ntensive **C**are **Nu**rses study] werd in 2005 uitgevoerd waarbij 5 van de 7 intensieve zorgafdelingen voor kinderen in België meegewerkt hebben. De verpleegkundigen werkzaam binnen deze afdelingen werden bevraagd over hun attitudes (aan de hand van stellingen en een 5-puntenschaal) en hun betrokkenheid bij medische beslissingen aan het levenseinde bij kinderen (aan de hand van de herinnering van het meest recent overleden kind op de afdeling bij wie een medische beslissing aan het levenseinde werd uitgevoerd) (hoofdstuk 4).

Resultaten

De resultaten van alle studies (en antwoorden op de onderzoeksvragen) zijn verwerkt in twee delen (een attitude deel en een betrokkenheid deel), onderverdeeld in zeven hoofdstukken. De nummering hieronder verwijst naar de onderzoeksvragen hierboven.

Attitudes

1a. Wat zijn de attitudes ten aanzien van euthanasie en andere medische beslissingen aan het levenseinde van verpleegkundigen die zorg dragen voor patiënten in het algemeen? (hoofdstuk 2 & 3)

De studie van 3327 verpleegkundigen toont aan dat bijna alle verpleegkundigen akkoord gaan met de praktijk van het onthouden of niet opstarten van een mogelijk levensverlengende behandeling (93%), met beslissingen om de pijn- en/of symptoomcontrole op te drijven met een mogelijk levensverkortend effect (96%) en met de praktijk van euthanasie voor patiënten met een terminale ziekte met extreme, oncontroleerbare pijn of ander lijden (92%). Niettegenstaande de hoge acceptatiegraad van euthanasie, gaat 70% van de verpleegkundigen akkoord dat goede palliatieve zorg vele verzoeken om euthanasie voorkomt. Slechts een minderheid van verpleegkundigen is bang voor misbruiken tengevolge van het toelaten van euthanasie of vreest voor een aangetaste arts-patiënt relatie. Meer dan de helft van de verpleegkundigen (57%) aanvaardt ook de praktijk van het toedienen van levensbeëindigende middelen zonder expliciet verzoek van de patiënt.

Verschillende factoren zijn geïdentificeerd die verschillen in attitudes kunnen verklaren, waarvan religie/levensbeschouwing en het belang dat eraan gehecht wordt in hun professionele houding t.o.v. levenseindebeslissingen bepalend is hoe verpleegkundigen staan tegenover euthanasie en levensbeëindiging in het algemeen, maar niet tegenover niet-behandelbeslissingen en het opdrijven van de pijn- en/of symptoomcontrole. Oudere verpleegkundige hebben een hogere aanvaarding van continue diepe sedatie, levensbeëindiging zonder verzoek en geloven meer in de preventieve kracht van palliatieve zorg op euthanasie. Het al dan niet ervaring hebben met het zorg dragen voor patiënten aan hun levenseinde speelt geen rol.

1b. Wat zijn de attitudes ten aanzien van euthanasie en andere medische beslissingen aan het levenseinde van verpleegkundigen die zorg dragen voor terminaal zieke kinderen? (hoofdstuk 4)

Verpleegkundigen werkzaam in pediatrische intensieve zorgafdelingen gaan in grote aantallen akkoord dat verder behandelen niet altijd in het belang van het kind is (90%) en dat toekomstige levenskwaliteit van het kind mee in overwegingen mogen genomen worden (91%). Slechts een minderheid van de verpleegkundigen vindt het ethisch steeds fout om het overlijden van het kind te versnellen door het toedienen van een middel (6%) en een meerderheid zou zelfs in bepaalde gevallen bereid zijn mee te werken aan het toedienen van een middel om het terminaal lijden van een kind te verkorten (78%). Daartoe vindt 89% dat de wetgeving zou moeten aangepast worden om in sommige gevallen het beëindigen van het leven van een kind mogelijk te maken.

2. Hoe zien verpleegkundigen hun rol binnen euthanasie en andere beslissingen aan het levenseinde? (hoofdstuk 2 & 3)

De analyses van de stellingen gaande over hoe verpleegkundigen hun rol zien in beslissingen aan het levenseinde tonen aan dat verpleegkundigen vinden dat ze moeten betrokken worden bij het hele proces m.b.t. levenseindebeslissingen omwille van hun centrale rol in de zorg voor een patiënt. Vooral wanneer bij een patiënt levensbeëindigende middelen zullen toegediend worden (89% akkoord) en wanneer bij een patiënt wordt beslist niet verder te behandelen (78% akkoord), vinden de meeste verpleegkundigen dat dit vooraf met de betrokken verpleegkundigen moet besproken worden. Twee derde (67%) vindt ook dat patiënten vaker verpleegkundigen aanspreken over beslissingen aan het levenseinde dan dat ze artsen erover aanspreken. Grotere onenigheid bestaat over hun overtuiging of artsen bereid zijn om naar hun meningen te luisteren en of verpleegkundigen zich hiërarchisch in een ondergeschikte positie bevinden die het hen moeilijk maakt om hun meningen mee te delen. Ten slotte zien we ook een grote verdeeldheid over hun bereidheid om middelen toe te dienen: 43% zou bereid zijn om in bepaalde gevallen middelen toe te dienen met het uitdrukkelijke doel het levenseinde van de patiënt te bespoedigen. Slechts 16% vindt dat het toedienen van middelen in euthanasie een taak is die een verpleegkundige zou mogen uitvoeren.

Verschillende multivariate logistische regressies zijn uitgevoerd om na te gaan in hoeverre meningen verschillen al naargelang bepaalde groepen verpleegkundigen. De setting waarin de verpleegkundige werkzaam is, is een belangrijke factor. Zo zien verpleegkundigen binnen de thuiszorg een minder actieve rol in levenseindebeslissingen dan verpleegkundigen binnen rusthuizen en ziekenhuizen. Andere opvallende verbanden zijn dat mannelijke verpleegkundigen een actievere rol zien in het toedienen van levensbeëindigende middelen dan vrouwelijke verpleegkundigen. Gelijkaardige verbanden zijn er ook bij religieuze versus niet-religieuze verpleegkundigen.

Betrokkenheid

3. Hoe vaak worden verpleegkundigen door een arts geconsulteerd in verschillende medische beslissingen aan het levenseinde? (hoofdstuk 5 & 6)

Aan de hand van secundaire analyses op gegevens van de sterfgevallenstudies kan nagegaan worden hoe vaak de arts aangeeft dat h/zij de beslissing aan het levenseinde voorafgaandelijk met een verpleegkundige heeft besproken. In 2007 heeft de arts in 51% van alle levenseindebeslissingen overlegd met een verpleegkundige. Dit overleg komt het vaakst voor in rusthuizen (66%), gevolgd door ziekenhuizen (50%) en komt het minst voor in de thuiszorg (36%). In vergelijking met 1998 is het overleg met verpleegkundigen gestegen, zij het in geringe mate, namelijk van 44% in 1998 tot 51% in 2007 van alle medische beslissingen aan het levenseinde. Deze stijging zien we binnen alle drie de settings, maar is het meest zichtbaar binnen de thuiszorg (van 21% naar 36%).

In hoofdstuk 6 hebben we ook onderzocht of dit overleg vaker voorkomt in bepaalde type levenseindebeslissingen. Er zijn geen significante verschillen in overleg naargelang het gaat over het toedienen van levensbeëindigende middelen, het opdrijven van de pijn- en/of symptoombestrijding met een mogelijk levensverkortend effect of het onthouden of niet opstarten van een mogelijk levensverlengende behandeling. De arts overlegt wel vaker met een verpleegkundige indien h/zij de intentie heeft om het levenseinde van de patiënt te bespoedigen dan wanneer h/zij die intentie niet heeft, zo ook overlegt h/zij vaker bij lager dan wel bij hoger opgeleide patiënten (binnen instellingen).

4. Hoe zijn verpleegkundigen die zorg dragen voor terminaal zieke kinderen betrokken in medische beslissingen aan het levenseinde? (hoofdstuk 4)

De overgrote meerderheid van verpleegkundigen die werkzaam zijn op pediatrische intensieve zorgafdelingen (85%) heeft in de laatste twee jaar persoonlijk een kind verzorgd bij wie een medische beslissing met een mogelijk levensverkortend effect is genomen. In 88% is een mogelijk levensverlengende therapie stopgezet of niet opgestart; in 72% is de pijn- en/of symptoombestrijding geïntensiveerd met een mogelijk levensverkortend effect en in 34% is een middel toegediend met de uitdrukkelijke bedoeling het leven te beëindigen. In de meeste gevallen (83%) start iemand anders dan een verpleegkundige de discussie over de beslissing aan het levenseinde. In 50% is een verpleegkundige betrokken in de besluitvorming. Vervolgens geeft 90% van de verpleegkundigen aan dat ze een rol hebben bij de uitvoering van deze beslissing. In de meeste gevallen zijn ze aanwezig bij de uitvoering om de patiënt en/of de naasten te steunen (77%) en/of zijn ze betrokken bij de praktische voorbereiding (65%). In geval van het toedienen van een middel met het uitdrukkelijke doel het leven te beëindigen geven 8 van de 13 verpleegkundigen aan dat ze de beslissing hebben uitgevoerd in aanwezigheid van de arts en 4 zonder de aanwezigheid van de arts.

5. Hoe zijn verpleegkundigen betrokken in euthanasie en het toedienen van levensbeëindigende middelen zonder verzoek van de patiënt? (hoofdstuk 5, 6 & 7)

Aan de hand van de Nu-ELD studie uitgevoerd bij verpleegkundigen en de sterfgevallenstudie uitgevoerd bij artsen zijn gegevens verzameld over de betrokkenheid van verpleegkundigen in euthanasie en in de toediening van levensbeëindigende middelen zonder expliciet verzoek van de patiënt. De arts overlegt met een verpleegkundige in 54% van alle euthanasiegevallen: in rusthuizen doet de arts dit in alle gevallen; in een ziekenhuis in 59%; en wanneer de patiënt thuis overlijdt in 44%. Wanneer de patiënt geen expliciet verzoek doet, consulteert de arts een verpleegkundige in 40% van de gevallen. Voor de verschillende settings is dit respectievelijk 63%, 42% en 17%. In de verpleegkundige studie geeft 64% van de verpleegkundigen aan dat ze betrokken zijn in de besluitvorming, wat inhoudelijk vaker inhoudt dat de verpleegkundige de

arts enkel informatie aanlevert (45%) dan dat ze samen tot een besluit komen (24%).

Wat betreft de toediening van middelen rapporteert de arts dat in 27% van alle euthanasiegevallen, de verpleegkundige het middel toedient. Dit komt het meest voor in ziekenhuizen (43%). In de verpleegkundige studie verklaart 12% van de verpleegkundigen middelen toe te dienen in kader van een euthanasie (14 gevallen). In de meeste gevallen gaat het over het toedienen van morfine of andere opiaten (9 gevallen), doch in sommige gevallen ook spierverslappers en/of barbituraten (5 gevallen). Dit gebeurt altijd in opdracht van de arts, maar de arts is in de meeste gevallen niet aanwezig (9 gevallen). Bovendien geeft 40% van de verpleegkundigen ook aan dat ze een voorbereidende handeling m.b.t. de middelen hebben.

In de gevallen waarbij het leven van de patiënt beëindigd wordt zonder uitdrukkelijk verzoek zijn verpleegkundigen op een gelijkaardige manier betrokken in het besluitvormingsproces, zij het dat artsen dit iets lager inschatten (40% versus 54% in geval van euthanasie). Verpleegkundigen dienen echter wel vaker het middel toe dan bij euthanasie (45% versus 12% in de verpleegkundige studie en 52% versus 27% in de arts studie). In de meeste gevallen betreft dit het toedienen van morfine (76%), en in sommige gevallen van spierverslappers en/of barbituraten (20%). In meer dan de helft van de gevallen is de arts niet aanwezig tijdens deze toediening (58%).

Verpleegkundigen die zorg dragen voor patiënten die thuis sterven en oudere verpleegkundigen zijn minder in de besluitvorming van het gebruik van levensbeëindigende middelen betrokken dan verpleegkundigen werkzaam in ziekenhuizen of rusthuizen en jongere verpleegkundigen (hoofdstuk 7). Naast een hogere kans dat verpleegkundigen het middel toedienen wanneer de patiënt geen expliciet verzoek heeft gedaan, is de kans ook hoger dat ze dit doen bij oudere patiënten en wanneer ze meer ervaringen hebben met levenseindebeslissingen. Vooral mannelijke verpleegkundigen die werkzaam zijn in ziekenhuizen, en in iets mindere grote mate vrouwelijke verpleegkundigen in ziekenhuizen, hebben een veel grotere waarschijnlijkheid middelen toe te dienen dan verpleegkundigen werkzaam in andere settings (hoofdstuk 7).

Ten slotte is ook nagegaan of er een evolutie is van de consultatie- en toedieningsgraad voor en na het in voege treden van de euthanasiewetgeving. In euthanasie zijn verpleegkundigen in 2007 vaker geconsulteerd dan in 1998 (54% versus 30%) en hebben ze minder vaak het middel toegediend (27% versus 40%). Deze stijging in consultatie en daling in toediening is zichtbaar binnen alle settings (hoofdstuk 5).

6. Hoe beschouwen verpleegkundigen continue diepe sedatie en hoe zijn ze erin betrokken? (Hoofdstuk 8)

In onze studie rapporteren 252 verpleegkundigen dat ze zorg gedragen hebben voor een patiënt die medicatie werd toegediend om hem/haar tot aan overlijden buiten bewustzijn te brengen. In 28% van die gevallen beschouwt de verpleegkundige de beslissing genomen met het uitdrukkelijke doel het overlijden van de patiënt te bespoedigen, en in 48% mede met het doel. Ze zijn van oordeel dat deze beslissing zeker levensverkortend is in 44% en mogelijk levensverkortend in 51%. In 9% van de gevallen zijn onenigheden gerapporteerd, en in 4% heeft de verpleegkundige bezwaren tegen de beslissing (hoofdstuk 8). De attitude studie onder verpleegkundigen toont aan dat 57% van de verpleegkundigen akkoord gaat met de stelling dat continue diepe sedatie een optimaal stervensproces is, zeker indien het lijden van de patiënt alleen zo onder controle kan worden gebracht (hoofdstuk 3). Slechts 26% vindt het een goed alternatief voor euthanasie; 31% beoordeelt dit als neutraal (hoofdstuk 4).

Verpleegkundigen communiceren regelmatig met de naasten over wensen m.b.t. continue diepe sedatie (67%), meer dan dat ze er met de patiënt over spreken (25%). Vooral binnen de thuiszorg bespreken verpleegkundigen de wensen van de patiënt en/of diens naasten, meer dan in rusthuizen en ziekenhuizen. In de helft van alle gevallen van continue diepe sedatie is de verpleegkundige betrokken in de besluitvorming van de arts rond continue diepe sedatie. Artsen zullen daartoe vaak de verpleegkundige om informatie vragen over de toestand van de patiënt (44%) en de mening van de naasten (36%). In 23% van de gevallen maken arts en verpleegkundige de beslissing tot continue diepe sedatie samen. De meeste verpleegkundigen (73%) evalueren de samenwerking met de arts als positief. Indien de mening van de verpleegkundige over de continue diepe sedatie wordt gevraagd, dan is er een hogere kans dat de verpleegkundige de samenwerking als positief ervaart.

Discussie/Aanbevelingen

Hoofdstuk 9 van het proefschrift behandelt eerst de sterktes en zwaktes van de studies die aangewend werden om onze onderzoeksvragen te beantwoorden. Nadien worden de resultaten van de studies bediscussieerd en aanbevelingen geformuleerd naar beleid, praktijk en verder onderzoek. Hieronder geven we enkele belangrijke discussiepunten en aanbevelingen.

Attitudes

Verpleegkundigen hebben een hoge aanvaarding van verschillende beslissingen aan het levenseinde die een mogelijk of zeker levensverkortend effect hebben, inclusief euthanasie. Er is ook een aanzienlijke groep verpleegkundigen die zelfs het toedienen van levensbeëindigende middelen zonder expliciet verzoek van de patiënt aanvaarden, een praktijk die zich binnen de illegaliteit situeert. Verpleegkundigen staan heel dicht bij de patiënt en worden heel direct geconfronteerd met het lijden van de patiënt. Ze werken ook heel patiëntgericht.

Ze hebben bovendien geen bevoegdheden naar het nemen van dergelijke beslissingen wat aanvaarden gemakkelijker maakt. Bovendien zijn er in België drie belangrijke wetten waaronder de euthanasiewet die maken dat artsen en verpleegkundigen kunnen werken binnen een legaal kader. Die wetgevingen en maatschappelijke debatten daarmee gepaard zullen hoogstwaarschijnlijk bijgebracht hebben aan die hoge aanvaardbaarheid.

Naast de hoge aanvaarding van euthanasie, is er ook een meerderheid van verpleegkundigen die geloven in een palliatieve zorg filter. Verpleegkundigen geloven zowel in goede palliatieve zorg als in de mogelijkheid tot euthanasie, die elkaar niet hoofdzakelijk hoeven tegen te spreken. Slechts een minderheid vreest dat het toelaten van euthanasie zou leiden tot misbruiken of tot een aangetaste arts-patiënt relatie wat relevant is voor landen die een wetgeving zouden overwegen. Verpleegkundigen staan midden in de zorg en zouden dergelijke negatieve gevolgen opmerken.

De gegevens tonen ook aan dat verpleegkundigen die de Katholieke doctrine volgen minder euthanasie aanvaarden, terwijl hun levensovertuiging geen invloed heeft op de andere beslissingen aan het levenseinde. Belangrijke nuance hierbij dat er toch een aanzienlijke groep is die dergelijke overtuigingen kunnen opzij zetten en toch euthanasie aanvaarden. Een ander belangrijk verschil in attitude zien we tussen jongere en oudere verpleegkundigen waarbij de laatste groep een grotere aanvaarding heeft op verschillende vormen van pijn- en symptoom-behandeling, ook al als dit kadert binnen de illegaliteit. We kunnen dit enerzijds verklaren door de hogere graad van ervaring met levenseindepraktijken, anderzijds door dat oudere verpleegkundigen anders werden opgeleid, binnen een sociale context waar “het zorg dragen” meer centraal staat, terwijl bv. in de huidige opleiding meer aandacht wordt besteed aan “patiëntautonomie, wettelijk kader, enz.”.

Attitudes ten aanzien van hun rol
Verpleegkundigen zien voor zichzelf een belangrijke rol in beslissingen aan het levenseinde omdat ze zich bewust zijn van hun positie die ze innemen ten aanzien van de patiënt. Ze staan heel dicht bij de patiënt en diens naasten, zijn goed op de hoogte van hun toestand, wensen,... en kunnen daartoe een bijdrage leveren aan de besluitvorming van de arts. Deze laatste zou niet altijd een hoge luisterbereidheid aan de dag leggen, zo ook vinden bepaalde verpleegkundigen dat ze hiërarchisch ondergeschikt staan waardoor ze hun mening moeilijk kunnen formuleren. Verpleegkundigen zien voor zichzelf een belangrijke rol weggelegd, maar ondervinden her en der toch moeilijkheden. Onze studies tonen ook aan dat ze daadwerkelijk niet altijd betrokken worden in besluitvorming wat de discrepantie versterkt.

Specifiek in geval van euthanasie, beschouwen verpleegkundigen dat ze een rol hebben in het horen van een euthanasieverzoek en in de besluitvorming. Meer variatie zien we in hoe verpleegkundigen hun rol in het toedienen van de middelen zien. Enkel een minderheid vindt deze toediening een taak die een

verpleegkundige zou mogen uitvoeren, maar een aanzienlijke groep zou wel bereid zijn om dit in bepaalde gevallen te doen. In welke omstandigheden is niet duidelijk, maar het lijkt erop dat ze dit zouden doen omdat de arts het van hen vraagt; in normaal medisch handelen delegeren artsen vaak de taken naar verpleegkundigen. Verpleegkundigen zijn bovendien heel begaan met de patiënt en diens naasten, en vinden vaak dat hun lijden moet gelenigd worden, en als het niet anders kan, desnoods door zelf levensbeëindigende middelen toe te dienen. Verpleegkundigen geven bovendien aan dat niet alle verpleegkundigen op de hoogte zijn wat ze wel of niet mogen uitvoeren in kader van een euthanasie.

Betrokkenheid
Ten eerste is het opvallend dat slechts in de helft van de *levenseindebeslissingen* een arts overlegt met een verpleegkundige, vooral omdat verpleegkundigen wel duidelijk aangeven betrokken te willen worden wat eerder zou wijzen dat artsen niet altijd bereid zijn om verpleegkundigen te consulteren. Ze zullen ze wel vaker consulteren wanneer het gaat over ingrijpender beslissingen wanneer ze de intentie hebben om het leven van de patiënt te beëindigen, bij lager opgeleide patiënten en in bepaalde zorgsettings. Interdisciplinair overleg tussen artsen en verpleegkundigen vertonen nog veel tekorten.

In *euthanasie* is dit overleg ook niet optimaal, ook al dat dit overleg een expliciete wettelijke vereiste is. Blijkbaar zijn wettelijke vereisten ook geen voorwaarden voor het induceren van een dergelijk overleg. Bovendien blijkt uit de Nu-ELD studie dat dit overleg hoofdzakelijk inhoudt dat de arts de verpleegkundige om informatie vraagt eerder dan dat het gaat over een wezenlijke bijdrage in de besluitvorming. Niet enkel dient er meer interdisciplinair overleg te zijn, dit overleg zou ook nog meer kwalitatief ingevuld mogen zijn. Een positieve noot is echter dat dit overleg met de jaren gestegen is (voor en na de wetgeving), maar of dit effect enkel te verklaren is door de wetgeving kan niet bevestigd worden. Een mogelijke andere verklaring zou kunnen zijn dat jongere generatie artsen en verpleegkundigen beter met elkaar kunnen communiceren.

Ook opvallend zijn de gegevens over de betrokkenheid van verpleegkundigen in de uitvoering van *euthanasie* en *levensbeëindiging zonder expliciet verzoek*. Ten eerste hebben verpleegkundigen vaak voorbereidende taken, zoals het afhalen en voorbereiden van de middelen. Dergelijke taken zijn onder medisch normaal handelen verpleegkundige taken, maar deze levenseindebeslissingen vallen niet onder normaal medisch handelen en vallen bijgevolg buiten de verpleegkundige bevoegdheden. De euthanasiewet voorziet echter niet in het specificeren van welke taken verpleegkundigen wel of niet mogen uitvoeren. Vervolgens dienen verpleegkundigen ook regelmatig de middelen toe en dat beperkt zich niet enkel tot de toediening van opiaten. Het is algemeen zo dat verpleegkundigen vaak dergelijke middelen in kader van de pijn- en symptoombestrijding toedienen; het is één van hun fundamentele taken tijdens het verlenen van levenseindezorg. Wanneer echter dergelijke middelen toegediend worden met het uitdrukkelijke doel het leven van de patiënt te beëindigen, dan bevinden verpleegkundigen zich in een legaal precaire situatie. Daarenboven dienen verpleegkundigen ook

spierverslappers en barbituraten toe, wat doet veronderstellen dat de verwarring met taken die zich situeren onder normaal medisch handelen zich niet altijd voordoet. Bovendien is het handelen op vraag van de arts geen uitsluitsel op het kunnen vervolgd worden (vooral in die gevallen waar er geen expliciet verzoek van de patiënt is en/of andere voorwaarden van de wet niet vervuld zijn). Een positieve noot is echter dat over de jaren heen verpleegkundigen minder vaak dergelijke middelen hebben toegediend, hoewel dit nog niet optimaal is. Er is een wetgeving die toelaat dat enkel artsen euthanasie mogen uitvoeren, maar dit wordt nog te vaak gedelegeerd naar verpleegkundigen.

In de gevallen dat de patiënt geen verzoek uit, hebben verpleegkundigen zelfs nog een meer intensieve rol. Ze dienen nog vaker de middelen toe wat te verklaren is door de gelijkenis met het intensiveren van de pijn- en/of symptoomcontrole. Dezelfde middelen worden toegediend door dezelfde mensen (verpleegkundigen) maar de intentie is fundamenteel verschillend, namelijk dat de middelen worden toegediend met het doel het leven van de patiënt te beëindigen en niet meer enkel met het doel pijn en lijden te lenigen. Dit belangrijk onderscheid heeft blijkbaar niet voor alle verpleegkundigen als gevolg dat ze hun opgelegde taken anders invullen en/of weigeren.

Vervolgens hebben we ook nagegaan in welke mate verpleegkundigen betrokken zijn in de praktijk van *continue diepe sedatie*. Verpleegkundigen dienen vaak de middelen toe en doen ook de intensieve follow-up. Ook in het komen van een dergelijke beslissing kunnen verpleegkundigen een wezenlijke bijdrage hebben. Onze studie toont ook aan dat de naasten van de patiënt vaak met verpleegkundigen communiceren over wensen, maar opnieuw is ook duidelijk dat artsen hen niet altijd betrekken in hun besluitvorming. Dit zou nochtans een positief gevolg hebben op de tevredenheid van verpleegkundigen in deze praktijk. Daarnaast volgt uit onze studie dat verpleegkundigen continue diepe sedatie als een heel complexe praktijk beschouwen, en het onderscheid met levensbeëindigend handelen vinden zij niet altijd even evident. Aangezien verpleegkundigen midden in de praktijk van continue diepe sedatie staan, mogen hun meningen daaromtrent niet onderschat worden.

Belangrijke verschillen tussen zorgsettings

Onze studies tonen duidelijk aan dat thuisverpleegkundigen een minder intensieve rol zien in beslissingen aan het levenseinde en daadwerkelijk ook veel minder betrokken zijn dan verpleegkundigen werkzaam in rusthuizen en ziekenhuizen. Patiënten die thuis sterven worden behandeld door hun huisarts met wie ze meestal een langdurige en vertrouwelijke relatie onderhouden; verpleegkundigen zijn niet altijd betrokken in de zorg; het betreft vaker kankerpatiënten, jongere en hoger opgeleide patiënten met wie de huisarts een goede communicatie mee onderhoudt; huisartsen zijn gewoon om alleen te werken en thuisverpleegkundigen werken meestal in een andere organisatie waar dat structureel overleg met huisartsen ontbreekt. In rusthuizen komt de huisarts op bezoek; het betreft vaker oudere patiënten met meerdere complexe

aandoeningen met wie communicatie niet altijd nog even vlot verloopt; verpleegkundigen staan in voor de dagelijkse zorg en zijn er altijd beschikbaar. Dit verklaart hun hogere betrokkenheid in de besluitvorming. Ten slotte zien we een opmerkelijk verschil in ziekenhuizen waar dat verpleegkundigen vaker levensbeëindigende middelen zullen toedienen. Deze setting kenmerkt zich door de structurele hiërarchische verhouding tussen specialisten en verpleegkundigen, met de eerste in een bevelende functie en de laatste in een uitvoerende functie. Het dagelijkse medisch handelen wordt gedelegeerd naar verpleegkundigen en dat breidt zich ook uit naar het uitzonderlijke medisch handelen.

Aanbevelingen voor praktijk, beleid & verder onderzoek

Verschillende aanbevelingen zijn opgesteld. Samenvattend zetten we enkele op een rij:

- Meer interdisciplinair overleg tussen artsen en verpleegkundigen is aanbevolen. Vooral binnen de thuiszorg is dit een extra uitdaging daar het structureel overleg er ontbreekt.
- De verantwoordelijkheden en rollen van verpleegkundigen in euthanasie dienen uitgeklaard te worden. Aangezien daarvoor een wettelijk kader voorzien is, kunnen aanbevelingen vastgehaakt worden aan deze, zij het in een wettelijke aanvulling, zij het in nationale richtlijnen. In richtlijnen kan de betrokkenheid van verpleegkundigen in overleg verder geconcretiseerd worden. Wat betreft de betrokkenheid tijdens de uitvoering van de euthanasie kan duidelijk gesteld worden welke taken door verpleegkundigen op zich kunnen genomen worden en welke niet. Belangrijk aan richtlijnen is dat die ook goed geïmplementeerd worden in de praktijk.
- Verpleegkundigen werkzaam in pediatrische intensieve zorgafdelingen hebben ook een leidraad nodig in levenseindepraktijken daar ze er een belangrijke rol uitoefenen. Door de aanwezige structuur in dergelijke afdelingen kan interdisciplinair overleg zeker gerealiseerd worden. Tegelijkertijd zouden ze ook een belangrijke zeggingschap kunnen hebben in publieke debatten over het al dan niet aanvaarden van het toedienen van levensbeëindigende middelen bij kinderen.
- Een andere belangrijke aanbeveling is dat de verschillende levenseindepraktijken duidelijk onderscheiden moeten worden in de praktijk. Verpleegkundigen dienen goed op de hoogte te zijn van de ethische, wettelijke en normatieve connotaties van verschillende levenseindebeslissingen.
- Binnen de levenseindepraktijken dient continue diepe sedatie ook duidelijk onderscheiden te worden van “normale” pijn- en/of symptoombehandeling. Duidelijke communicatie tussen de arts en verpleegkundigen met duidelijke meldingen over intenties en voorziene gevolgen dienen gecommuniceerd te worden. Zo ook kunnen verpleegkundigen een wezenlijke bijdrage hebben in het komen tot een dergelijke beslissing die toch een complexe besluitvorming met zich kan meebrengen. Het onderscheid met levensbeëindigend handelen dient ook geëxpliciteerd te worden.
- In het algemeen kan gesteld worden dat de opleiding aandacht dient te hebben voor bovenstaande aanbevelingen, niet enkel binnen de

verpleegkundige opleidingen, maar ook binnen de artsenopleiding. In beide beroepsgroepen kan de communicatie tussen zorgverleners onderling en naar de patiënt en diens naasten over het levenseinde in het algemeen geoptimaliseerd worden. Artsen dienen daarbij de meerwaarde van de verpleegkundige opinies en bijdrage te onderkennen en verpleegkundigen kunnen assertiever worden om deze bijdrage op te eisen. Ook zou een verhoogde kennis over ethische en legale aspecten, symptoomcontrole, medicatie aan het levenseinde en hun effecten, palliatieve zorg, enz. kunnen bijdragen aan een verhoogde kwaliteit van levenseindezorg voor patiënten en hun naasten.

- Verpleegkundigen kunnen in belangrijke mate bijdragen in onderzoek over kwalitatieve levenseindezorg. Zo ook dient de impact van hun meer intensieve bijdrage aan besluitvorming gemeten te worden, bv. in termen wat de bijdrage is aan de kwaliteit van de levenseindezorg. Ook dienen meer nuances van hun attitudes bestudeerd te worden, hoe artsen de rol van verpleegkundigen zien en hoe zij hun betrokkenheid beschrijven. Van beide beroepsgroepen zou meer onderzoek verricht moeten worden hoe ze hun rol percipiëren en wat ze van hun eigen, maar ook van de andere beroepsgroep verwachten. Ten slotte zijn internationale studies aangewezen om verpleegkundige betrokkenheid in levenseindepraktijken te kunnen vergelijken.

Curriculum Vitae

Els Inghelbrecht, born August 11, 1977 (Ostend, Belgium), studied Latin-Mathematics in high school. At Ghent University she finished her Masters degree in Clinical Psychology in 2001 and her Masters degree in Criminology in 2003. She started work at the Vrije Universiteit Brussel in 2004 as a researcher in the Department of Human Ecology, Faculty of Medicine, on a one-year research project for the Policy Research Centre Traffic Safety. Since 2005 she has worked at the End-of-Life Care Research Group, Department of Medical Sociology, Faculty of Medicine on a project financed by the Fund for Scientific Research Flanders about the attitudes and involvement of nurses in medical end-of-life decisions.

LIST OF PUBLICATIONS

Articles in international peer-reviewed journals

Inghelbrecht E, Bilsen J, Mortier F, Deliens L. The role of nurses in physician-assisted dying: retrospective study in Belgium. CMAJ 2010 (Early release, published at www.cmaj.ca on May 17, 2010). [Impact factor 2008: 7.559]

Inghelbrecht E, Bilsen J, Mortier F, Deliens L. Nurses' attitudes towards end-of-life decisions in medical practice: a nationwide study in Flanders, Belgium. Palliative Medicine 2009; 23(7):649-58. [Impact factor 2008: 1.872]

Inghelbrecht E, Bilsen J, Mortier F, Deliens L. Attitudes of nurses towards euthanasia and towards their role in euthanasia: a nationwide study in Flanders, Belgium. International Journal of Nursing Studies 2009; 46(9): 1209-18. [Impact factor 2008: 2.115]

Inghelbrecht E, Bilsen J, Pereth H, Ramet J, Deliens L. Medical end-of-life decisions: experiences and attitudes of Belgian pediatric intensive care nurses. American Journal of Critical Care 2009; 18(2):160-8. [Impact factor 2008: 2.043]

Inghelbrecht E, Bilsen J, Mortier F, Deliens L. Factors related to the involvement of nurses in medical end-of-life decisions: a death certificate study. International Journal of Nursing Studies 2008; 45(7):1022-31. [Impact factor 2008: 2.115]

Articles in national journals

Inghelbrecht E, Bilsen J, Mortier F, Deliens L. Betrekken artsen verpleegkundigen in levenseindebeslissingen? Hospitals.be 2008;6(3):23-32.

Inghelbrecht E, Bilsen J. Wanneer sterven nabij is. Nursing 2007; 13; NVKVV Nieuwseditie juli/augustus 2007, 2-3.

Chapters in books

Inghelbrecht E. Betrokkenheid van verpleegkundigen in levenseinde-beslissingen. In: L. Deliens, M.A. Echteld, B.D. Onwuteaka-Philipsen (eds), Medische en verpleegkundige praktijk in Nederland en België. Bohn Stafleu Van Loghum, Houten, 2009: 151-56.

Other publications

Inghelbrecht E, Bilsen J, Mortier F, Deliens L. Continuous deep sedation: nurses' involvement in decision-making. European Journal of Palliative Care 2009; 10 (1),23-4.

Inghelbrecht E. Uitbreiding euthanasiewet wenselijk volgens verpleegkundigen, Recht op waardig sterven 2009, 27(119): 11.

Inghelbrecht E, Bilsen J, Mortier F, Deliens L. Nurses' attitudes towards end-of-life decisions in Flanders, Belgium. Palliative Medicine 2008; 4(22): 513-4.

Inghelbrecht E, Bilsen J, Pereth H, Ramet J, Deliens L. Medical end-of-life decisions in Belgian pediatric intensive care units: nurses' involvement and attitudes. Archives of Public Health 2007; 65(Suppl1): 31.

Inghelbrecht E, Bilsen J, Mortier F, Deliens L. Involvement of nurses in medical end-of-life decisions. Palliative Medicine 2006; 20(3): 112.

Inghelbrecht E, Bilsen J, Mortier F, Deliens L. Communicatie tussen verpleegkundigen en artsen, patiënten en naasten in niet-behandelbeslissingen. Nederlands Tijdschrift voor Palliatieve Zorg 10(1):23-24.

Inghelbrecht E, Bilsen J, Pereth H, Ramet J, Deliens L. Medische beslissingen aan het levenseinde in pediatrische intensieve zorgafdelingen in België: betrokkenheid en attitudes van verpleegkundigen. Nederlands Tijdschrift voor Palliatieve Zorg 8(2):57.

Inghelbrecht E, Willems B, Bernheim J. De impact van whiplash ten gevolge van een verkeersongeval op de kwaliteit van het leven: een pilootstudie. Steunpunt Verkeersveiligheid, mei 2005.

Inghelbrecht E. Psychopathie en hersendisfuncties: een kritische analyse. Universiteit Gent, 2003.

Inghelbrecht E. De rol van comorbiditeit bij drop-out, participatie in behandeling en behandelingsresultaat in geval van illegaal druggebruik. Universiteit Gent, 2001.

Presentations

Inghelbrecht E. Betrokkenheid van verpleegkundigen bij medische beslissingen aan het levenseinde. Bijscholing voor verpleegkundigen werkzaam in een algemeen ziekenhuis, St Jans Ziekenhuis Campus Serruys, 11/02/2010.

Deschepper R, Inghelbrecht E. Voorafgaande zorgplanning. HGZO-congres: Ethiek in de zorg - ICT in het onderwijs, Brussel, 19/11/2009.

Inghelbrecht E. In welke mate communiceren verpleegkundigen met artsen, patiënten en naasten in niet-behandelbeslissingen. 6e Vlaams Congres Palliatieve Zorg, Brugge, 13/10/2009.

Inghelbrecht E. Continuous deep sedation: nurses' involvement in decision-making. 11th Congress of the European Association for Palliative Care, Vienna, 7/05/2009.

Bilsen J, Inghelbrecht E. Verpleegkundige betrokkenheid bij End-of-Life Decisions. 35ste week van de Verpleegkundigen en Vroedvrouwen, Oostende, 24/03/2009.

Inghelbrecht E. Rol van verpleegkundigen in de besluitvorming bij euthanasie. 6e Vlaams-Nederlands onderzoeksforum palliatieve zorg, Rotterdam, 20/03/2009.

Inghelbrecht E. Een praktijkstudie over de handelingen van de arts en de verpleegkundige in het levenseinde van de patiënt. LEIF Nurses, Wemmel, 17/02/2009.

Inghelbrecht E. Nurses' attitudes towards end-of-life decisions in Flanders, Belgium. 5th Research Forum of the European Association for Palliative Care, Trondheim, Norway, 29/05/2008.

Inghelbrecht E. Attitudes van verpleegkundigen ten aanzien van beslissingen aan het levenseinde. Wit-gele kruis Vlaams-Brabant, Herent, 26/02/2008.

Inghelbrecht E. Een praktijkstudie over de handelingen van de arts en de verpleegkundige in het levenseinde van de patiënt. LEIFnurses, Wemmel, 19/02/2008.

Inghelbrecht E. Attitudes van verpleegkundigen ten aanzien van beslissingen aan het levenseinde. Wit-gele kruis Vlaams-Brabant, Diest, 19/02/2008.

Inghelbrecht E. Medical end-of-life decisions in Belgian pediatric intensive care units: nurses' involvement and attitudes. 9th Public Health Symposium: Public Health at the End of Life, Brussels, 14/12/2007.

Inghelbrecht E. Medische beslissingen aan het levenseinde in pediatrische intensieve zorgafdelingen in België: betrokkenheid en attitudes van verpleegkundigen. Wetenschap in de palliatieve zorg: 5e Onderzoeksforum Palliatieve Zorg Nederland Vlaanderen, UA, Antwerpen, 17/11/2007.

Inghelbrecht E. Medical end-of-life decisions in Belgian pediatric intensive care units: nurses' involvement and attitudes. 3e Levenseinde Informatieforum, recht op zorg, zorg om recht - 4 jaar wetgeving inzake patiëntenrechten, palliatieve zorg en euthanasie, Brussel, 24/03/2007.

Inghelbrecht E. Involvement of nurses in medical end-of-life decisions. 4th Research Forum of the European Association for Palliative Care, Venice, Italy, 25/05/2006.

Bilsen J, Inghelbrecht E. Betrokkenheid van verpleegkundigen bij medische beslissingen rond het levenseinde. Masteropleiding Verpleeg- en vroedkunde,

Symposium Onderzoek en Praktijk in dialoog. Orale presentatie op de plenaire sessie: Problematiek rond het levenseinde. Universiteit Antwerpen, 9/11/2006.

Bernagie K, Audenaert K, Inghelbrecht E, Jacobs F, Dierickx R, Van Heeringen C. Diathesis for impulsive behaviour: Personality and psychiatric components. Poster presented at the BCNBP congress - Annual forum: neurobiology of violence, Antwerp, 25/10/2002.