The euthanasia practice in Belgium
Behavior and attitudes regarding reporting and adherence to legal safeguards

Tinne Smets

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MELC monitoring quality of end-of-life care

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Chapter 8 – 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. J Pain Symptom Manage 2011 *(in press).*

Preface and acknowledgements

One of the most complex and challenging medical and societal debates today surrounds the issue of euthanasia. Questions concerning the possibility of efficient societal control over the euthanasia practice and how to safeguard the carefulness of this medical practice are often at the forefront of the debates. The possibility of societal control over the practice of euthanasia is a prerequisite for effective legislation. This book provides insight into the medical practice of euthanasia in Belgium with a specific focus on physicians' adherence to legal safeguards and their reporting of euthanasia cases. By so doing, we hope to offer valuable data driven information to evaluate the implementation of the euthanasia law in Belgium and to inform debates about the legalization of euthanasia that are currently going on in many countries.

This book was written as a PhD dissertation. It is the final product of the collaboration and contribution of so many people without whom this work would not have been possible. To those people, I would like to express my sincere gratitude and appreciation.

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Tinne Smets
Brussels, January 2011

PART 1
INTRODUCTION

CHAPTER 1
INTRODUCTION

1.1 Background

During the last century, the circumstances of dying have changed substantially in developed societies. Achievements in public health and improved living conditions have led to an increase in life expectancy. Consequently, the number of elderly people in the population has risen.[1] In the past century there has been a significant shift in causes of death, from a predominance of deaths due to infectious diseases such as cholera, typhus, measles and smallpox to deaths caused by chronic and degenerative diseases. Degenerative diseases, such as cardiovascular disease, cancer, and stroke are now the major causes of death in developed European societies.[2] As a consequence of this epidemiological transition, death is nowadays more likely to be preceded by a longer dying process and increasing numbers of people experience a terminal illness phase at the end of life.

Curing disease and prolonging life have traditionally been the main goals of medical care. Advances in medical diagnostic and therapeutic possibilities throughout the last decades have increased the possibilities of medical treatment and have expanded options for sustaining or prolonging the life of the terminally ill.[3] A patient loosing vital functions for instance, can for a long period be kept alive due to the technological possibilities. However, the drawbacks of this progress have also become apparent and criticisms of futile treatments that either have a low probability of having an effect or produce an effect that is of no benefit to the patient have surfaced. Paradigms in medicine are shifting more and more from a 'quantity of life' approach to a 'quality of life' approach. It is now generally recognized that treatment aimed at cure is not always beneficial or justified and in some cases the patient's quality of life can become more important than prolonging his or her life. Preserving the quality of the patient's remaining life and alleviating their suffering have become important goals of end of life care and, [4-6] in some instances, hastening death at the request of a patient may be an acceptable or even desirable outcome of end of life care.[7] Euthanasia is an ethically laden decision and places societies for the issues of allowing it or not, and if so, of how to control the practice.

1.2 Medical end-of-life decisions

A point may be reached when a minimal quality of life can no longer be maintained and those involved may feel that prolonging life is no longer desirable. In such instances, medical end-of-life decisions can be made that will possibly or certainly hasten the death of the patient.[7] These decisions may involve withholding futile aggressive treatment, but may go as far as intentionally hastening death with life-ending drugs. Medical end-of-life

decisions with a possible or certain life-shortening effect are usually classified in five main categories: (1) non-treatment decisions, (2) the intensification of the alleviation of pain and symptoms, (3) euthanasia, (4) physician-assisted suicide, and (5) life-ending drug use without the patient's explicit request (see box 1)[8,9] The latter three end-of-life decisions can be categorized under the term physician-assisted death.

Box 1: Overview of medical end-of-life decisions with possible or certain life-shortening effect and definitions

1. *Non-treatment decision*: the withholding or withdrawing of treatment, taking into account the possibility or the certainty that this will hasten the patient's death
2. *Intensification of the alleviation of pain and symptoms* by using drugs (e.g. morphine) taking into account a possible life-shortening side effect or with a co-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
5. *Life-ending drug use without the patient's explicit request:* the administration of drugs with the explicit intention to end life without an explicit request of the patient

Continuous deep sedation until death, another important practice at the end of life, has been differentiated from these medical end-of-life decisions. Continuous deep sedation until death involves the administration of drugs to keep a patient continuously in deep sedation or coma until death.[10-12] Often, the decision to start continuous deep sedation goes along with the decision to forgo the administration of artificial nutrition and hydration.[13] The status of continuous deep sedation with regard to end-of-life decisions with a possible or certain life-shortening effect is unclear and much discussed; it is unclear whether or not continuous deep sedation has a life-shortening effect. Some consider it a form of slow euthanasia [14,15] while others find it is a good palliative intervention that should be clearly distinguished from euthanasia.[16,17]

Of the many ways in which doctors can influence the manner and timing of a patient's death, some are accepted as normal medical practice, for example the withholding of a disproportionate treatment or the intensification of pain and symptom treatment even at the risk of hastening death.[7] Other end-of-life decisions, namely physician-assisted suicide and euthanasia, are not considered part of normal medical practice and are legally tolerated under strict conditions only in a few countries and states worldwide.[7] Euthanasia itself is legal only in the Netherlands, Belgium and recently also in Luxembourg;[18-20] physician-assisted suicide can be practiced legally in the US States of Oregon and Washington, in the Netherlands, in Luxembourg, and in Switzerland. The status

of physician-assisted suicide is less clear in Belgium, but the Federal Control and Evaluation Committee Euthanasia (further referred to as the Federal Review Committee) regards physician-assisted suicide as a form of euthanasia if it is carried out in the presence of a physician and in accordance with the due care requirements set out in the euthanasia law.[18-24]

Before euthanasia was legalized in 2002, euthanasia was a punishable offence in Belgium. Criminal law did not recognize the concept of euthanasia, but the articles on voluntary manslaughter and murder applied. The status of assisted suicide was less clear. According to some, assisting in suicide was not a criminal offence as the act of suicide itself was not punishable. According to others, assisted suicide was punishable as so-called 'criminal negligence' or 'failing to aid a person in grave danger.' [25-28]

Although the practice of euthanasia remains illegal in most countries, growing support for it can be observed among the general public in many developed countries.[29,30] The increasing debate and growing support for euthanasia and self-determination at the end of life can be seen as a reflection of the growing urge for control over and the wish to plan major life events that characterizes our contemporary western society.[1,31] Support for euthanasia and for the legalization of the practice is generally much lower among physicians. [32-34]

1.3 The Belgian euthanasia law

1.3.1 The process of legal change

The issue of euthanasia has long divided society and politicians in Belgium. Several reasons can be deduced from the Parliamentary proceedings as to why politicians thought the practice of euthanasia needed to be regulated in Belgium.[31,35,36] Firstly, realizing that euthanasia was taking place, politicians wanted to provide legal security for physicians who perform it and for patients who request it. Physicians who performed euthanasia could, prior to the euthanasia law, call on the juridical concept of 'the state of necessity', ie a situation in which a physician has to chose between two conflicting duties, the relief of unbearable suffering by ending life and the duty to preserve life, and is forced to chose the first as compliance with the law would be likely to involve greater harm than would violating it. However, as there was no case law on euthanasia, it was unclear whether the 'state of necessity' would be accepted as a basis of justification for euthanasia. For patients it was uncertain whether their autonomous decisions would be respected. Secondly, paradigms in medicine had shifted from medical paternalism to patient autonomy and euthanasia was regarded as the epitome of self-determination that had to be

legally recognized. Thirdly, by legalizing euthanasia the state wanted to protect patients against abuse of medical power which had revealed itself in the sizable practice of the use of life-ending drug without the explicit request of the patient.[37] Dying patients also all too often became victim of futile medical treatment as physicians were afraid of acting in a way that could possibly hasten death. Fourthly, a study had revealed that a clandestine practice of euthanasia existed in Belgium.[37] It was deemed undesirable that physicians decided on euthanasia requests according to their own individual standards. Lawmakers wanted to provide more transparency and openness and to create societal control over the existing practice of euthanasia. The last reason a euthanasia law was urged was the observation that due to the epidemiological transition, more and more people will experience a terminal illness phase at the end of life and may end up in a hopeless situation without prospect of improvement, which they may experience as pointless.[31]

In the eighties and the nineties proposals for a euthanasia bill were regularly introduced and discussed in the Belgian Federal Parliament.[33,38,39] However, none of these bills became law as the Christian Democrats, who were uninterruptedly the most important political faction in government from the 1950s onwards, were against the legalization of euthanasia.[33] In light of these bills, however, an advice on the desirability of the legal regulation of the practice of euthanasia was requested from the Advisory Committee on Bioethics. The Advisory Committee was a multidisciplinary body and was ideologically and linguistically balanced. The advice of the Committee was not unanimous, but comprised four different proposals.[40]

The first proposal related to a change in the Penal Code to legalize euthanasia and determined the conditions under which euthanasia could be legally allowed.

The second proposal observed the existing restrictions in the Penal Code, but introduced conditions that made it possible for the physician to make an appeal on the basis of a 'state of necessity.' The proposal also contained a procedure to control euthanasia *a posteriori*: a physician who performs euthanasia would be required to complete a document that he or she would have to transfer to the judicial authorities via the medical examiner.

The third proposal also upheld the restrictions in the Penal Code and set out legal conditions covering the grounds on which a physician could appeal on the 'state of necessity.' The proposal also contained a procedure to control *a priori*, not only euthanasia, but all important medical end-of-life decisions. This procedure entailed an evaluation by a third person appointed by a local ethical committee. Additionally, the proposal related to an *a posteriori* control of euthanasia by society or by the judicial authorities.

The last proposal upheld the position that euthanasia should under no conditions be allowed. The advice of the Advisory Committee for Bioethics resulted in debates over euthanasia in the Senate in 1997 and acted as a catalyst for public debate.

When, in 1999, Christian Democrats were for the first time in forty years no longer represented in government and a coalition government of Liberals, Socialists, and Greens was formed, ethically progressive legislation on euthanasia became possible.[33] After new hearings in the Senate, several different proposals for a euthanasia bill were introduced.[41] The common premise underlying virtually all the proposals was the right of the individual to autonomously make end-of-life decisions. Shorty after the issue of euthanasia had been placed on the parliamentary agenda, the coalition parties came up with a bill that formed a compromise between their different proposals. The majority proposal on euthanasia was linked to proposals for bills concerning palliative care and establishing a Committee to control and evaluate euthanasia practice. A procedure to control euthanasia *a posteriori* through a Control and Evaluation Committee Euthanasia was incorporated in the final version of the majority bill on euthanasia. In the final bill, the Penal Code remained unchanged and the bill on euthanasia itself determined the conditions under which euthanasia would no longer be considered a crime.[41] The euthanasia bill was finally approved on May 28, 2002; a bill on palliative care was approved almost simultaneously on June 14, 2002.

In the euthanasia bill as finally approved, physician-assisted suicide was not included. Throughout the polarized Parliamentary discussions on euthanasia, assisted suicide had come to mean simply killing someone at their request with no additional conditions, and proponents of the euthanasia bill did not want to be accused of supporting such practices. The bill was furthermore limited to individuals who had attained the age of majority; the subject of euthanasia for minors was so controversial that including it would have threatened approval of the bill. Furthermore, a 'palliative filter' requirement, ie a requirement to consult a specialized palliative care team, proposed and endorsed by many politicians, was not included in the final bill either, because acceptance of the amendment to include it would have delayed the legislative process too much. However, according to the euthanasia law, a physician may make his or her willingness to grant a request for euthanasia subject to additional requirements, so a 'palliative filter' can still be required by individual physicians and health care institutions.[27,39]

1.3.2 Comparison with the Netherlands

Euthanasia was also legalized in the Netherlands in 2002 [42] but the process of legal change had been very different from that in Belgium. The process was very gradual in the Netherlands and was accompanied more by a societal process of discussion and consensus. The Netherlands had already developed a gradual legal tolerance of euthanasia under strict conditions decades before the practice was officially legalized. The norms and procedures that governed the practice had largely emerged from within the medical profession itself and were later adopted by the courts in the context of criminal prosecutions.[39,43-45] The country had also devised and been using procedures for reporting and controlling euthanasia since the early nineties.[39,43,44] These procedures were evaluated and revised several times to refine them in order to stimulate physicians to report their cases. The Dutch euthanasia Act of 2002 is considered as the codification of the norms and procedures that had ruled the practice for almost three decades.

Compared with the Netherlands, the introduction of legislation in Belgium has taken place over a much shorter time span and was to a much larger extent a parliamentary process. Although it was known that euthanasia occurred in Belgium, the country did not have the same permissive approach towards it as the Netherlands. Discussion of euthanasia became possible only in the middle of the 1990s, which was much later than in the Netherlands. The explanation for this can be found in Catholic thinking, which has long had societal and political influence in Belgium. Secularization came later in Belgium than in the Netherlands, where the influence of Christian thinking had already disappeared from society in the 1960s.[39] For as long as the Catholic denomination (in the form of the Christian Democrat party) took part in the government coalition, it was successful in preventing discussion and regulation of euthanasia. Only since the nineties, a significant part of the societal base that supported denominational segregation had fallen, and the Christian Democrats adopted a more tolerant position on ethical matters.[33,39]

In contrast with the Netherlands also, there was no relevant jurisprudence on euthanasia in Belgium and no guidance was offered for self-regulation from the medical profession itself. The Belgian Medical Association was of the conviction that euthanasia was better left to the medical profession itself. Whereas in the Netherlands the law on euthanasia was essentially a formalization of rules introduced and applied by the profession, from the point of view of many physicians the Belgian law on euthanasia was a top-down affair that exemplified the intrusion of politics into medical practice.[44,46] Belgium thus did not have the same experience-based gradual development of norms and of systems for societal control as the Netherlands. The euthanasia law of 2002 and

the reporting, control and evaluation procedures were largely based on the Dutch model. [46,47]

1.3.3 The due care requirements of the euthanasia law

According to the euthanasia law in Belgium, euthanasia is considered to be 'intentional life-ending by someone other than the person concerned at the latter's explicit request.' [19] To make a legitimate request for euthanasia, the patient must be an adult, must be conscious and legally competent at the moment of making the request, and must be in a condition of constant and unbearable physical or psychological suffering resulting from a serious and incurable disorder caused by illness or accident, for which medical treatment is futile and there is no possibility of improvement.

The law furthermore specifies that the physician must have several conversations with the patient in which he or she ascertains whether the patient experiences their suffering as constant and unbearable. The physician must also inform the patient about his or her medical condition, their prospects, and possible alternative treatments, including the option of palliative care. The physician must in each case consult another independent physician about the serious and incurable character of the condition. If there is a nursing team that has regular contact with the patient, the physician must also discuss the request for euthanasia with the nursing team or its members. If the patient so desires, the physician must additionally discuss the request with the patient's relatives, and must be certain that the patient has had the opportunity to discuss it themselves with whomsoever they wish.

Finally, to make societal control over the practice of euthanasia possible, the physician who performs the act is required to report the case of euthanasia to the Federal Control and Evaluation Committee Euthanasia for review.[19] Reporting has to be done within four days of performing euthanasia. The objective of this reporting procedure is to establish a formalized and uniform registration method for all physicians in Belgium and to allow the Federal Review Committee to evaluate the carefulness of the practice as described in the euthanasia law. If a physician was considered not to have acted carefully in accordance with the due care requirements of the law, the Federal Review Committee can ask the physician for additional information on the case and if necessary report it to the judicial authorities for further investigation (see Chapter 2 for a more extensive discussion of the reporting, control and evaluation procedures).[19]

The euthanasia law does not only apply to terminally ill patients (ie. those who are expected to die in the near future).[19] Euthanasia in non-terminally ill patients is possible under the same strict due care requirements as for terminally ill patients, but two additional due care requirements must be taken into account. Firstly, before carrying out euthanasia, the physician is required to consult a third independent physician who must be either a psychiatrist or a specialist in the illness from which the patient suffers. Secondly, there must be at least one month between the patient's request and the performance of the euthanasia.[19] It is the treating physician based on his or her medical knowledge who determines whether a patient is terminally or non-terminally ill.

The euthanasia law also stipulates the possibility of performing euthanasia on a patient in an irreversible coma or persistent vegetative state based on a written advance euthanasia directive. Every legally competent person of age including emancipated minors who are no longer under parental control can draw up an advance directive instructing a physician to perform euthanasia in the case that they end up in an irreversible coma or a persistent vegetative state and thus no longer able to express their will. The physician who performs euthanasia based on an advance directive must ascertain that the patient suffers from a serious and incurable disorder caused by illness or accident and is in an irreversible coma or persistent vegetative state. All the other due care requirements and procedures of the euthanasia law also apply. An advance directive is only valid if it is drafted or confirmed no more than five years prior to the person's loss of the ability to express his or her wishes.[19]

1.4 This dissertation

1.4.1 Study objectives and research questions

By studying the reported practice of euthanasia, this dissertation will give insight into the degree to which the goals of transparency, public oversight and legal control of euthanasia are achieved in Belgium.

As in the Netherlands [48-50], the practice of euthanasia has been researched several times in Flanders, Belgium. These studies, conducted in 1998, 2001 and 2007, have assessed the trends in euthanasia.[37,49,51,52] In 1998, 1.1% of all deaths in Flanders were the result of euthanasia.[37] In 2001, during the process of legalization of euthanasia, the incidence of euthanasia sharply decreased to 0.3%.[49] The decrease in the incidence may have been caused by fear of judicial action among physicians in the midst of the legalization process.[47] Five years after legalization, the incidence of euthanasia had increased to 1.9% of all deaths [51], probably because in the new legal climate the use of lethal drugs can

be more openly discussed with patients, relatives and other healthcare workers without fear of judicial action and has now become an accepted option at the end of life.[51]

While the incidence and characteristics of euthanasia and other end-of-life practices have been investigated several times, the degree to which societal control over the practice of euthanasia has been achieved in Belgium has not. Debates about the legalization of euthanasia often relate to concerns about the possibility of effective societal control over the practice and of keeping the practice within agreed borders.[53-56] One of the aims of the euthanasia law was to enhance societal control over the existing practice of euthanasia.[36] In this dissertation, we will first describe how societal control over euthanasia is organized in Belgium and compare the reporting, control, and evaluation procedures for euthanasia in Belgium with those that exist in the Netherlands. Secondly, we will estimate the rate to which physicians report their cases of euthanasia to the Federal Review Committee, and see where and how the transparency of the euthanasia practice can be further improved by exploring the reasons physicians give for not reporting and the factors associated with reporting and non-reporting of euthanasia. To gather more insight into the practice of euthanasia, we will investigate the characteristics of reported and unreported cases, the degree to which physicians adhere to the legal safeguards in medical practice and their reasons for non-adherence. Finally, we will investigate the attitudes of physicians towards the use of life-ending drugs and towards the euthanasia law. As physicians were not involved in the discussions leading to the euthanasia law and were not asking for euthanasia legislation, these issues are of particular interest.

The following study objectives and research questions will be addressed in this dissertation.

To study how societal control over the practice of euthanasia is organized in Belgium and in the Netherlands (Part 1 of this dissertation)

1. What do the reporting, control and evaluation procedures for euthanasia entail in Belgium and in the Netherlands? What are the similarities and differences in the procedures between both countries? *(Chapter 2)*
2. What are the possible implications of the differences in the procedures for a safe and controllable euthanasia practice? *(Chapter 2)*

To study physicians' reporting of cases of euthanasia to the Federal Control and Evaluation Committee, and to gain more insight into physicians' adherence and non-adherence to legal safeguards in medical practice (Part 2 of this dissertation)

1. What are the characteristics of the reported cases of euthanasia in Belgium? Has there been a change in the characteristics over the years? What are the similarities and the differences between the characteristics of the reported cases of euthanasia in Belgium and in the Netherlands? *(Chapters 3 and 4)*
2. What is the rate of reporting of euthanasia cases to the Federal Control and Evaluation Committee? *(Chapter 6)*
3. What reasons do physicians have for not reporting cases of euthanasia, and what are the factors that are associated with reporting and non-reporting of cases of euthanasia? *(Chapters 6 and 7)*
4. To which degree do physicians in Belgium adhere to the legal due care criteria for euthanasia in medical practice? What are their reasons for non-adherence? *(Chapter 5)*
5. Are there differences between reported and unreported cases of euthanasia with regard to the characteristics of due care? *(Chapter 6)*

To investigate the attitudes of physicians in Belgium towards the use of life-ending drugs and towards the euthanasia law, and to study their experiences with euthanasia (Part 3 of this dissertation)

6. What are Belgian physicians' attitudes towards the use of life-ending drugs and towards the euthanasia law? Which factors are associated with these attitudes? *(Chapter 8)*
7. Which factors predict whether or not a physician has ever performed euthanasia? *(Chapter 8)*

1.4.2 Methodologies

This dissertation is based on four different studies.

Study of official databases of reported cases of euthanasia from the Belgian Federal Control and Evaluation Committee and the Dutch Regional Euthanasia Review Committees

We studied all 1,917 cases of euthanasia reported by physicians in Belgium to the Federal Review Committee between implementation of the euthanasia law on September 22, 2002, and December 31, 2007. The anonymous databases were made available to us by the Committee for research purposes. The databases consisted of information collected from the official standardized euthanasia registration forms sent in by the reporting physicians.[57] Based on an analysis of the databases we were able to study the characteristics of all reported cases of euthanasia in Belgium since implementation of the euthanasia law.

We also studied the anonymous databases of the Dutch Regional Euthanasia Review Committees and compared the characteristics of the reported cases of euthanasia and physician-assisted suicide in Belgium and in the Netherlands.
Chapters 3 and 4 provide more information about the data collection and the registration forms.

Death certificate study

A post-mortem survey on end-of-life decisions using a representative sample of death certificates was performed in Flanders, Belgium in 2007. The study protocol has been published in BMC Public Health.[58] The response rate for this study was 58.4%. A stratified at random sample was drawn of persons deceased between 1 June 2007 and 30 November 2007 in Flanders, Belgium. The certifying physician of each included death was sent a questionnaire on end-of-life decision-making in the case concerned. The principal aim of the survey was to estimate the incidence of medical end-of-life decisions with a possible or certain life-shortening effect. The survey allowed us to estimate the total number of euthanasia cases performed in Flanders in 2007. The survey also included a question on whether or not the physician had reported the death to the Federal Review Committee, allowing us in addition to estimate the reporting rate of euthanasia, and to compare reported and unreported cases of euthanasia. Reasons for non-reporting were also requested.
See chapter 6 for more in-depth information on the methodology of this study.

The SENTI-MELC study, a retrospective study via the Belgian Sentinel Network of General Practitioners

A large-scale mortality follow-back study was performed in 2005-2006 to monitor end-of-life care and decision-making in Belgium using the Sentinel Network of General Practitioners (SENTI-MELC study). It concerned a quantitative registration study of deaths in GP practices within the Belgian Sentinel Network. The study resulted in a representative sample of 1,690 non-sudden deaths. The study protocol has been published elsewhere.[59] GPs registered deaths weekly and immediately after they had learned of them, using a standardised form. A large interview study was subsequently conducted with physicians who had reported the death of a patient who was at least one year old and had died non-suddenly at home or in a care home. In this dissertation we study data of nine interviews conducted with GPs who had reported a death that was the result of euthanasia. Particularly of importance for this dissertation were the questions assessed in the interviews on the GP's adherence and non-adherence to the legal due care requirements, and the reasons for non-

adherence. Questions were asked on the patient's medical situation during the final months of life and at the time the decision on euthanasia was made, on whether or not the physician had informed the patient about their medical situation and prospects of improvement, on consultation and reporting of euthanasia, and on the performance of euthanasia. See chapter 5 for more information of the SENTI-MELC study.

Nationwide physician survey

In 2009 we conducted a nationwide questionnaire survey among physicians who were likely to be involved in the care of dying patients. Physicians from the following specialties were included: general practice, anesthesiology, gynecology, internal medicine, neurology, oncology, pulmonology, neuropsychiatry, psychiatry, cardiology, radiotherapy and surgery. The questionnaire was sent to 3,006 physicians; the response rate of the study was 34% (N=914). Questions were asked about the socio-demographics of the physician, work-related characteristics, attitudes towards the use of life-ending drugs and towards the euthanasia law, and practices concerning euthanasia. Physicians were further presented with five hypothetical cases of a patient in the final stage of a terminal disease who was suffering severely. In each hypothetical case, we varied between whether or not the patient explicitly requested life-ending, the drugs administered to the patient, the mode of administration, and the extent of life-shortening. These hypothetical cases allowed us to assess how physicians label different end-of-life decisions, which end-of-life decisions they define as euthanasia and should therefore be reported, and which factors are associated with the reporting of euthanasia to the Federal Review Committee. See chapters 7 and 8 for more information on the methodology of this study.

In all four studies strict anonymity of the physicians and patients was guaranteed.
The databases from the Review Committees contained only anonymous information on all reported cases of euthanasia, so the identity of patient and physician could not be uncovered.
In the death certificate study a lawyer was used as intermediary between responding physicians, researchers, and the Flemish Agency for Care and Health guarantee total anonymity of physicians and patients.
Strict procedures were also used to preserve patient anonymity and physician confidentiality in the SENTI-MELC study. Patient names were never identifiable to the interviewers or to other members of the research group: GPs used anonymous codes to refer to patients in the registration form and the interviewers gave them closed envelopes with patient information before the

interview to make sure that they gave information about the correct patient. After the study the identity of the GP was permanently deleted from all files.
As in the death certificate study, a lawyer was also used as intermediary between responding physicians and researchers in the nationwide physician survey to make sure the identity of the responding physicians could not be retrieved.

1.4.3 Outline of this dissertation

This dissertation is made up of four parts: part 1 provides the background, in part 2 studies on reporting of euthanasia and adherence to legal safeguards are presented, in part 3 a study on physicians' attitudes towards the use of life-ending drugs and towards the euthanasia law is described, and in part 4 methodological issues are discussed, the main findings are summarized, and a general discussion of the study results is provided (see table 1).

Part 1 of this dissertation contains two chapters.
Following this introductory chapter, Chapter 2 describes and compares the legal reporting, control and evaluation procedures for euthanasia in Belgium and the Netherlands and describes the possible implications of the differences between the procedures for a safe and controllable euthanasia practice. The findings presented in chapter 2 are the result of a study of all relevant official documents relating to the Belgian and Dutch notification, control and evaluation procedures for euthanasia.

Part 2 of this dissertation contains Chapters 3 to 7.
Chapter 3 presents the results of the study of all cases of euthanasia reported to the Federal Control and Evaluation Committee between the implementation of the euthanasia law and the end of 2007. In this chapter, the characteristics of all reported cases of euthanasia are presented.
Chapter 4 describes and compares the characteristics of the reported cases of euthanasia and physician-assisted suicide in Belgium and the Netherlands. This study was based on an analysis of the anonymous databases of the reported cases of euthanasia in Belgium and the Netherlands.
Chapter 5 describes the results of nine interviews with general practitioners who were responsible for a case of euthanasia. These interviews provide insight into GPs' adherence and non-adherence to the due care requirements of the euthanasia law. Their reasons for non-adherence to the due care requirements are also explored.
Chapter 6 presents the results of the retrospective death certificate study. In this chapter, the reporting rate for euthanasia in Flanders is estimated, and the reported and unreported cases of euthanasia are compared with regard to

characteristics of due care. For the unreported cases of euthanasia, reasons for non-reporting are explored.
Chapter 7 describes the results from the physician survey with regard to the five hypothetical cases. In this chapter we investigate which end-of-life decisions physicians in Belgium think qualify as euthanasia and should be reported, which end-of-life decisions they would they report themselves, and the factors that are associated with the correct labeling of a euthanasia case and with reporting knowledge and intentions.
Part 3 of this dissertation contains Chapter 8.
Chapter 8 presents the results of the nationwide physician survey with regard to physicians' attitudes towards the use of life-ending drugs and towards the euthanasia law. Factors associated with these attitudes and factors associated with the performance of euthanasia are also investigated.
Finally, Part 4 of the dissertation deals with methodological considerations, summarizes the main findings and provides a general discussion of the study results, with implications and recommendations for policy, practice and further research.

Table 1 Chapters in this dissertation are based on different studies

	Studies in this dissertation			
Issues in this dissertation	Databases of reported euthanasia cases	Death certificate study	SENTI-MELC study	Physician survey
Chapter 3 Reported cases of euthanasia in Belgium	X			
Chapter 4 Reported cases of euthanasia and physician-assisted suicide in Belgium and the Netherlands	X			
Chapter 5 Adherence to legal safeguards, reasons for adherence and non-adherence			X	
Chapter 6 Reporting rate of euthanasia, comparison reported and unreported cases of euthanasia, reasons for non-reporting		X		
Chapter 7 Labeling of end-of-life decisions, reporting knowledge and intentions				X
Chapter 8 Attitudes towards life-ending drug use and the euthanasia law				X

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CHAPTER 2
THE MEDICAL PRACTICE OF EUTHANASIA IN BELGIUM AND THE NETHERLANDS: LEGAL NOTIFICATION, CONTROL AND EVALUATION PROCEDURES

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Abstract

Objectives
To describe and compare current legal procedures for notifying, controlling and evaluating (NCE-procedures) euthanasia in Belgium and the Netherlands, and to discuss the implications for a safe and controllable euthanasia practice.
Methods
We systematically studied and compared official documents relating to the Belgian and the Dutch NCE-procedures for euthanasia.
Results
In both countries, physicians are required to notify their cases to a review Committee, stimulating them to safeguard the quality of their euthanasia practice and to make societal control over the practice of euthanasia possible. However, the procedures in both countries differ. The main differences are that the Dutch notification and control procedures are more elaborate and transparent than the Belgian, and that the Belgian procedures are primarily anonymous, whereas the Dutch are not. Societal evaluation is made in both countries through the Committees' summary reports to Parliament.
Conclusions
Transparent procedures like the Dutch may better facilitate societal control.
Informing physicians about the law and the due care requirements for euthanasia, and
systematic feedback about their medical actions are both pivotal to achieving efficient societal control and engendering the level of care needed when performing such far-reaching medical acts.

2.1 Introduction

Medical end-of-life decisions, including physician- assisted death, are known to occur in several countries.[1] This observation raises questions about whether or not euthanasia (i.e. intentionally ending a person's life by the administration of drugs at that person's explicit request) and physician-assisted suicide (i.e. intentionally assisting in a suicide of another person or providing another person with the means to commit suicide) can be part of good medical end-of-life practice. Currently, one of the main objections being raised against regulation of euthanasia and physician-assisted suicide is the so called slippery slope argument: if euthanasia were legalised it cannot be efficiently monitored and controlled and will lead to error, abuse, and the violation of the rights of vulnerable patients.[2-4] These arguments re-emerged when the Luxemburg Parliament recently discussed a euthanasia bill.[5]

A particular concern when any country considers permitting euthanasia or physician-assisted suicide is how to make sure the practice is adequately controllable and careful medical practice is guaranteed. Currently, only Belgium and the Netherlands have chosen to legalise officially the existing practice of physician-assisted death.[6] Belgium and the Netherlands have both faced the question of how to safeguard efficiently careful medical practice regarding euthanasia by devising monitoring systems which attempt to constrain the practice and by explicitly establishing both substantive and procedural safeguards against abuse (see table 1) in the euthanasia law.[7,8]

In the Netherlands euthanasia was only officially regulated in 2002, but the country had already developed a gradual legal tolerance of euthanasia under strict circumstances and in accordance with due care requirements developed by the medical profession itself.[9,10] For more than two decades the Dutch had also been taking practical steps to bring euthanasia and physician-assisted suicide under a regime of effective control.[11] Dutch physicians had for many years been encouraged by the Royal Dutch Medical Association (Koninklijke Nederlandse Maatschappij ter bevordering der Geneeskunst) to bring their life-ending acts into the open.[10] Since the early nineties procedures for notifying and controlling euthanasia had been developed, evaluated, and revised several times at the request of the government to refine them in order to increase physicians' willingness to notify their cases and enhance societal control.[12-15]

Table 1 Legal due care requirements in Belgium and the Netherlands [7,8]

Substantive requirements
- The patient's request must be voluntary and well-considered (BE/NL); it must be repeated, and may not be the result of any external pressure (BE).
- The patient must be in a medically futile state of constant and unbearable physical or psychological suffering which cannot be alleviated, resulting from a serious and incurable condition caused by illness or accident (BE).
- The patient's suffering must be lasting and unbearable (NL).
- The physician must inform the patient about his/her health condition and prospects (BE/ NL).
- The physician and patient must come to the belief that there is no reasonable prospect of improvement in the patient's situation (BE/NL).
- The physician must terminate life in a medically and technically appropriate way (NL).
Procedural requirements
- The treating physician must consult another physician before proceeding (BE/NL).
- The physician must notify the case of euthanasia for review (BE/NL).

Although euthanasia was known to take place in Belgium too, the country has not had the same permissive approach towards euthanasia and consequently does not have an experience-based gradual development of procedures for societal control like the Netherlands.[16] The Belgian euthanasia law was the result of a short Parliamentary process, preceded by debates in the media, in the Belgian Advisory Committee on Bioethics (Belgisch Raadgevend Comité voor Bio-Ethiek / Comité Consultatif de Bioéthique de Belgique) and among healthcare professional organisations. The legalisation process in Belgium was finalised quite quickly and without broad consensus among the medical profession. As a result the Belgian euthanasia law, including its procedures for societal control, was largely based on the Dutch model.[17,18]

While the process of legalisation was different, both countries have deemed ethical, legal and societal control over the medical practice of euthanasia a prerequisite for effective legislation. To make sure that euthanasia would be performed under the strict requirements of due care, legal and societal control was explicitly built into both euthanasia laws via regulated notification of euthanasia by physicians, control by a multidisciplinary committee and evaluation by the Parliament.

Questions concerning the possibility of efficient societal control over euthanasia and how to safeguard the carefulness of the practice are at the forefront of the debates on euthanasia that are currently taking place in several

countries. In this paper we aim to contribute to these debates by describing and comparing the current procedures for notifying, controlling and evaluating (NCE- procedures) euthanasia in Belgium and the Netherlands, and by discussing the implications for a safe and controllable euthanasia practice of the most important differences between them.

2.2 Materials and methods

We systematically studied and compared the relevant official documents relating to the Belgian and the Dutch NCE-procedures for euthanasia: the laws on euthanasia [7,8], the Dutch Burial and Cremation Act [19], rules concerning the working of the (Regional) Review Committee(s) Euthanasia [20,21], registration forms [22,23], Review Committee(s) summary report [24-28], and Parliamentary documents written as a result of debates on the Committees' summary reports.[29-31]

2.3 Results

2.3.1 Notification

Procedure

Both countries require physicians who performed euthanasia to report their cases to a review committee by means of a legally defined registration form. In Belgium the physician has to send the completed form directly to the Federal Control and Evaluation Committee Euthanasia (Federale Controle- en Evaluatiecommissie Euthanasie / Commission Fédérale de Contrôle et d'Evaluation de l'euthanasie).[8] In the Netherlands, as with all other cases of non-natural death, physicians must notify the medical examiner and must send a completed registration form plus several additional documents such as the report from the second, legally required, consulted physician to the medical examiner. The medical examiner then examines the body to determine how the euthanasia was performed and which substances were used, and sends a report on his or her findings together with the physician's registration form to one of five Regional Euthanasia Review Committees (Regionale Toetsingscommissies Euthanasie).[19]

Registration forms

As opposed to the Dutch notification procedure, the Belgian procedure was made anonymous at the request of the physicians. The Belgian registration form [22] is made up of two parts: one open part contains specifications about the age, gender and disease of the patient, place and date of death, and the euthanasia procedure followed. A second sealed part contains the identity of the patient, physician(s) and other persons involved. The Committee can decide to lift the anonymity and contact the physician for further information.[8] On the Dutch form the name of the notifying physician is openly mentioned and the Committee can contact the physician directly for additional information or clarification.[7] In general the Dutch form is more elaborate and contains more open-ended questions than the Belgian form (Table 2).

Table 2. Content of the registration forms in Belgium and the Netherlands [22,23]

TOPICS		BELGIUM	THE NETHERLANDS
Identification	**Patient**	- Name and address (sealed), place and date of birth and death, gender.	- Name, gender, age, date of death, town of death, place of death.
	Notifying physician(s)	- Name, address, registration number, signature, stamp (sealed).	- Name, gender, specialty, name of institution, work address, signature
	Consulted physician(s)	- Name, address, NIHDI* (RIZIV/INAMI) registration number, date of consultation (sealed).	- Name, specialty, nature of relationship with notifying physician and patient, date of consultation
	Other consulted persons	- Name, address, capacity, date of consultation (sealed).	- Who was consulted?
Medical condition of patient	**Disease**	- Nature of the severe and incurable illness from which patient suffered.	- Nature of the illness from which patient suffered. - Which medical therapies have been tried? - Was there a prospect of improvement?
	Suffering	- Give nature and description of persistent and unbearable suffering. - Give reasons why suffering could not be alleviated.	- Nature and description of suffering. - Was the suffering unbearable? - Was the suffering without prospect of improvement? - What has been done in the way of palliation? What was the result of that?

			- Were there still alternatives to alleviate the suffering? If so, how did patient feel about these alternatives?
	Normal life expectancy at time of euthanasia	- Could be expected that patient would die within foreseeable future?†	- In which time span was patient's death expected if life ending on request or assisted suicide had not taken place?
Request for euthanasia (or physician-assisted suicide)‡	**Current explicit request**	- Give elements that prove that patient's request was voluntary, well- considered, repeated and not the result of external pressure. - Request was discussed with patient† - Patient was informed about his or her medical condition† - Patient was informed about remaining therapeutic possibilities and consequences† - Patient was informed about palliative care and consequences† - There was a written request for euthanasia - Date of request† - Formulated, dated and signed by patient, or formulated, dated and signed, in the presence of a physician, by third party, chosen by patient and who has no material interest in the death of patient† - Reasons why patient was not capable of putting request in writing and sign it are	- When was the first time the patient has expressed a request? - When was the request repeated? - In the presence of who was the request expressed? - Are there indications that patient's request was expressed under the influence of others? - Was patient fully aware of the import of the request and his/her physical condition? How could this be judged? - Was termination of life or assisted suicide a topic of conversation before patient expressed request? In which context?

		mentioned† - There was persisting physical or psychological suffering† - Course of followed procedure and written documents are recorded in patient's medical file?	
	Written advance euthanasia directive	- There was an adequately formulated advance directive† Date of advance directive - Formulated, dated and signed by patient, or formulated, dated and signed, in the presence of a physician, by third party, chosen by patient and who has no material interest in the death of patient† - Reasons why patient was not capable of putting request in writing and sign it are mentioned, medical certificate that states this incapability was added.† - One or more confidants were appointed. † - Course of followed procedure and written documents are recorded in patient's medical file? † - Unconscious state of patient was irreversible†	- Was there an advance directive? Date of advance directive. - Do you know if patient had any advance directive before? How often did he or she draw one and on which dates? - If there is no written advance directive, why is that? - Written advance directive is to be added to registration form.

Consultation	**Specialty consulted physician(s)**	- What was specialty of consulted physician?	- Which physician(s) was/were consulted? What is their specialty?
	Independence of second physician from patient and consulting physician	- Date and advice of consultation?	-Were they co treater? What was their relation to you and to the patient?
	Consultation report		- Consultation report to be added to registration form.
	Other consulted persons	- Was the request discussed with members of nursing team? † - Was request discussed with significant others appointed by patient? †	- Was nursing or care givers team consulted? If so, who was consulted and what were their opinions? If not, why was that? - Did you discuss the termination of life with significant others? If so, who was consulted? What were their opinions? If not, why was that?
Performance of euthanasia (or physician-assisted suicide)	**Drugs used**	- Which method and substances were used?	- Which method and substances were used? - Was it a case of euthanasia or assisted suicide? - Who performed the euthanasia? - Who was, beside yourself, present at

	the moment of the life ending?

* National Institute for Health and Disability Insurance.
† Closed question
‡ The request for euthanasia (or physician-assisted suicide) can be based on a current explicit request or on a written advance euthanasia directive. The Belgian registration form makes a procedural distinction between the two forms of requests, the Dutch one does not. A written advance euthanasia directive instructing a physician to perform euthanasia can be drawn up for cases where one is no longer able to express one's will. The Belgian law prescribes that the patient has to be in an irreversible coma, the Dutch law does not impose this.

Table 3 Control procedure in Belgium and the Netherlands

	BELGIUM	**THE NETHERLANDS**
Committees	1 federal Control and Evaluation Committee Euthanasia	5 Regional Euthanasia Review Committees
	16 members, appointed on the basis of their knowledge and experience concerning the authorised matters. Committee members are appointed for 4 years, renewable.	3 members each Committee. Committee members are appointed for 6 years, renewable once
Composition per Committee	8 physicians (at least 4 of whom are professors); 4 professors of law or lawyers; 4 persons with experience in care for seriously ill patients criteria of balance: - language parity* - at least 3 candidates of each gender -pluralistic representation†	1 physician; 1 lawyer who is also Chair; 1 expert on ethical issues
	Substitute members are arranged. The Committee is chaired by one Dutch speaking and one French speaking chair who are chosen by the Committee members of the respective language group.	Substitute members are arranged. Each committee is chaired by a lawyer. .
Procedure	The Committee examines the registration forms	The Committees examine the registration forms sent

	sent in by the physicians.	in by the physicians.
	The Committee assesses -on the basis of part 2 (unsealed) - whether each case of euthanasia complies with the due care requirements.	The Committees assess whether each case of euthanasia or physician assisted suicide complies with the due care requirements.
	The Committee can make remarks or request further information from the physician concerned, but a majority vote is required for the anonymity of the document to be lifted	The Committees can make remarks or request further information (orally or in writing) from the physician concerned The committees can instigate an inquiry with the medical examiner, the consultant, or the caregivers, to evaluate the physician's actions.
Judgment and report	The Committee passes judgement within two months. No notification to the physician. The case will be closed if the due care requirements are met.	The Committees pass judgement within six weeks. Written notification to the physician. The case will be closed if the due care requirements are met.
	The case is forwarded to the King's Prosecutor for further investigation, when a 2/3 majority judge the due care requirements to be violated.	The case is forwarded to the Assembly of Prosecutors-General and the Regional Inspector for health care for further investigation, when 2 of the 3 Committee members judge the due care requirements to be violated.

***** The Committee is composed of eight Dutch speaking and eight French speaking members.
† The Committee is composed of members with different life stance

2.3.2 Control

Review Committees

In Belgium there is one Federal Control and Evaluation Committee Euthanasia whereas there are five Regional Euthanasia Review Committees in the Netherlands (Table 3).

Procedure

In both countries the control procedure requires that the Committees study the notified cases and determine whether euthanasia was performed in accordance with the legal due care requirements [7,8] (Table 3).
If the Committee judges that the due care requirements have been met, the case is closed. If it judges that the due care requirements have been violated, the case is forwarded for further investigation; in Belgium to the King's Prosecutor and in the Netherlands to the Assembly of Prosecutors-General and the Regional Inspector for health care.[7,8]
Up till now, no cases of euthanasia have been sent to the judicial authorities for further investigation in Belgium. In the Netherlands, 16 cases (0.21% of all notified cases) were sent to the judicial authorities in the first four years after the euthanasia law came into effect.[26-28]

In Belgium, all notified cases are initially dealt with anonymously; a majority vote within the Committee is required to lift the anonymity.[8] During the first 15 months of the implementation of the law anonymity was lifted in 31,5% of all notified cases.[24] This dropped to 22% during 2004 and 2005.[25] In the Netherlands all reporting physicians systematically receive a feedback report from the Committees [7] and all Dutch Committee decisions are published anonymously on the website of the Review Committees.[33]

2.3.3 Evaluation

In both countries, the Committees are legally required to draft summary reports on the basis of reported euthanasia cases to inform the public, to evaluate the implementation of the law, and, eventually, to make recommendations for adaptation of the law.[7,8] In Belgium these summary reports are biennially presented directly to Parliament; in the Netherlands Review Committees annually report jointly to the Minister of Health, Welfare and Sport, and the Minister of Justice, who in turn report to Parliament. Unlike in Belgium, the Dutch NCE- procedures are also scientifically evaluated several times.[12-15]

2.4 Discussion

One of the most important and difficult questions to be faced when considering the legalisation of euthanasia is how to make sure that the practice is adequately controllable. This paper describes and compares the notification, control and evaluation procedures for euthanasia in Belgium and the Netherlands. In both countries, these procedures are a crucial and integral part of the euthanasia law, requiring physicians to notify their cases, stimulating them to safeguard the quality of their euthanasia practice and thus to prevent abuse. However, the procedures in both countries differ. The Belgian notification procedure is less elaborate than the Dutch, and, whereas the Belgian notification procedure is primarily anonymous, the Dutch one is not. As a consequence, both countries developed different individual control mechanisms. Societal evaluation is made in both countries through the Committees' summary reports to Parliament.

This is the first study which systematically compares the NCE- procedures for euthanasia in Belgium and the Netherlands based on a thorough analysis of all relevant official documents. Not only did we compare the laws on physician-assisted death, we also included other official documents such as the registration forms, Committee summary reports and parliamentary documents. Therefore the study can add to the debate on how best to safeguard the carefulness of euthanasia practice.
A limitation is that we do not yet dispose of empirical data on the euthanasia practice in Belgium, and therefore cannot fully investigate the implications of the NCE- procedures in practice.

Because physicians are more likely to notify their euthanasia cases if they do not face the threat of immediate investigation by the Public Prosecution authorities, both countries installed review committees. In practice they function as a buffer between the physician and the criminal justice system, putting the emphasis in the assessment more on responsibility and education than on deterrence and punishment.[12] However, the existence of one central Committee to review all euthanasia cases, as is the case in Belgium, possibly provides a better guarantee of uniformity in the control of the medical practice of euthanasia than does the Dutch system of five Regional Review Committees.

Especially in the Netherlands, the NCE-procedures are elaborate and require effort to fulfil. They could therefore be experienced as burdensome by the physicians, and possibly make them less willing to comply with every legal due care requirement or to notify their cases. The burdensomeness of the

procedures might also influence physicians in choosing alternative options without as many procedural requirements such as terminal sedation.[14] However, research in the Netherlands indicates that many physicians experience this level of external control as supportive and feel relieved because they can share responsibility.[15] In this context the establishment of a network of specially trained and qualified physicians, who can be consulted by the treating physicians on all matters concerning euthanasia, including the NCE-procedures is very important. The need for expert consultation and advice was in the Netherlands and in Belgium (Flanders) met with the establishment of the SCEN (Support and Consultation for Euthanasia in the Netherlands) and LEIF (LifeEnd Information Forum) projects respectively. SCEN and LEIF physicians can be consulted by all physicians and are trained to give expert advice on euthanasia (and physician-assisted suicide in the Netherlands) and act as independent second physician in euthanasia requests. Leif physicians can also be consulted about other end-of-life decisions.[34]

Because Dutch physicians have to add additional documentation to the registration form, the Dutch Review Committees have more information available to them than the Belgian one which judges solely on the basis of the registration forms. Even though the Review Committees in both countries can always contact the physician for additional information, extensive notification dossiers might contribute to reaching better-grounded decisions.

Even though the anonymity of the Belgian notification procedure was established at the request of the physicians and thus might increase their willingness to notify, the systematic feedback from the Committees to physicians in the Netherlands improves the transparency of the Dutch notification procedure. Through direct exchanges with physicians, the Committees can contribute to the improvement of medical-professional decision-making in euthanasia practice. The feedback and the reports from the Committees have an important educational value and can promote the quality of the euthanasia practice because they give physicians a basis of knowledge for the careful practice of euthanasia. These aspects could provide strong motivation for physicians to notify. The latest research on end-of-life practices in the Netherlands estimated a notification rate of 80,2%, indicating that most euthanasia and physician-assisted suicide cases are actually being reported.[14] A notification rate for euthanasia in Belgium is yet to be estimated.

In the Netherlands only evaluation of the practice of euthanasia and the NCE-procedures has been supported by repeated and substantial scientific research for several years. Scientific research can be beneficial in Belgium too, e.g. to refine the procedures in order to enhance control over euthanasia and to provide objective findings on which to ground future policy decisions.

Absolute control over the practice of physician-assisted death is probably a utopian ideal, whether the practice is legalised or not, but Belgium and the Netherlands are clearly working step-by-step towards effective monitoring systems. The notification, control and evaluation procedures that were devised provide the possibility of safe and controllable euthanasia practice. The extensive comparison of these procedures and the discussion of their implications can be a guideline for other countries debating euthanasia legislation. Whether the euthanasia laws and the NCE- procedures, especially in Belgium, have also offered the intended protection and control in practice will have to be evaluated in further empirical research.

2.5 Conclusions

Belgium and the Netherlands have both attached great importance to developing thorough and detailed procedures for notifying and controlling euthanasia in medical practice. The main purpose of these procedures is to stimulate physicians to safeguard the quality of their euthanasia practice, to notify their cases for review, and to make societal control over the practice of euthanasia possible. Transparent procedures like the Dutch might better facilitate societal control. Information to physicians about the law and the due care requirements for euthanasia, and systematic feedback about their medical actions, are pivotal to achieving efficient societal control and engendering the level of care needed when performing such far-reaching medical acts.

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PART 2
REPORTING OF EUTHANASIA AND ADHERENCE TO LEGAL SAFEGUARDS

CHAPTER 3
LEGAL EUTHANASIA IN BELGIUM CHARACTERISTICS OF ALL REPORTED EUTHANASIA CASES

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Abstract

Objectives
To study the reported medical practice of euthanasia in Belgium since implementation of the euthanasia law.
Research design
Analysis of the anonymous database of all euthanasia cases reported to the Federal Control and Evaluation Committee Euthanasia.
Subjects
All euthanasia cases reported by physicians for review between implementation of the euthanasia law on September 22, 2002 and December 31, 2007 (n=1917).
Measures
Frequency of reported euthanasia cases**,** characteristics of patients and the decision for euthanasia, drugs used in euthanasia cases, and trends in reported cases over time.
Results
The number of reported euthanasia cases increased every year from 0.23% of all deaths in 2002 to 0.49% in 2007. Compared to all deaths in the population, patients who died by euthanasia were more often younger (82.1% of patients who received euthanasia compared to 49.8% of all deaths was younger than 80, $p<0.001$), men (52.7% versus 49.5%, $p=0.005$), cancer patients (82.5% versus 23.5%, $p<0.001$), and more often died at home (42.2% versus 22.4, $p<0.001$). Euthanasia was most often performed with a barbiturate, sometimes in combination with neuromuscular relaxants (92.4%) and seldom with morphine (0.9%). In almost all patients, unbearable physical (95.6%) and/or psychological suffering (68%) were reported. A small minority of cases (6.6%) concerned non-terminal patients, mainly suffering from neuromuscular diseases.
Conclusions
The frequency of reported euthanasia cases has increased every year since legalisation. Euthanasia is most often chosen as a last resort at the end of life by younger patients, patients with cancer, and seldom by non-terminal patients.

3.1. Introduction

In 2002 Belgium legalized euthanasia. Although there had been studies on the prevalence of euthanasia in Belgium [1,2] before it was legalized, and studies on attitudes towards euthanasia [3-6], little is known about the actual medical practice of euthanasia since legalization. The euthanasia law allows euthanasia - defined as intentional life-ending by a physician at the explicit request of a patient - on condition that all the due care requirements prescribed in the law are satisfied.[7,8] To make a legitimate euthanasia request the patient must be an adult, must be conscious and legally competent at the moment of making the request, and must be in a condition of constant and unbearable physical or psychological suffering resulting from a serious and incurable disorder caused by illness or accident, for which medical treatment is futile and there is no possibility of improvement. The physician decides whether the disorder is incurable based on the actual state of medicine, and the patient alone determines whether suffering is constant and unbearable.[9,10] The physician must have several conversations with the patient in which he ascertains whether the patient experiences his/her suffering as constant and unbearable. The physician must inform the patient about their medical condition, prospects, and possible alternative treatments, including palliative care. He must consult another independent physician about the serious and incurable character of the condition. This physician does not need to be a palliative care specialist. After performing euthanasia, the physician is required to report the case for review to the Federal Control and Evaluation Committee Euthanasia (the Committee). This Committee determines whether the reporting physician has complied with all legal due care requirements.[7] In case of irregularities the Committee can ask the physician for additional information and send the case to the judicial authorities.[11]

The Belgian euthanasia law is not limited to terminally ill patients who are expected to die within months.[7,12] A euthanasia request from a non-terminal patient who is in the same medical condition as mentioned above may also be granted under the same requirements of careful practice. However, a third physician, a psychiatrist or specialist in the illness from which the patient suffers, must be consulted, and there must be at least one month between request and performance of euthanasia.[7]

Currently, Belgium, The Netherlands, Luxembourg and the U.S. states of Oregon and Washington are the only places in the world that have legalized euthanasia and/or physician-assisted suicide. More and more countries and states, however, are considering legalization. In debates about euthanasia much attention is given to the possibility of effective societal control and to ways in which due care can be guaranteed.[13] Notification of euthanasia by physicians is pivotal to making societal control possible. The information collected by the

Committee over the years provides valuable insight into the euthanasia practice in Belgium. In this paper we will present data on all the reported euthanasia cases since implementation of the euthanasia law. In so doing, we aim to provide an overview of the practice of euthanasia in Belgium and offer useful information for countries considering similar legislation.

We will address the following research questions: How many euthanasia cases have been reported in Belgium since implementation of the euthanasia law in 2002? What are the demographic and clinical characteristics of these cases, and do they differ from the characteristics of all deaths in the population? What are the characteristics of the decision and performance of euthanasia? Are there differences in clinical characteristics between terminally ill and non-terminally ill patients receiving euthanasia? And, do the characteristics of euthanasia cases evolve over the years?

3.2 Methods

3.2.1 Data Sources

The data presented in this article are based on the databases of officially reported euthanasia cases in Belgium (Wallonia, Flanders and Brussels) between the implementation of the euthanasia law on September 22, 2002 and December 31, 2007. This database consists of information collected from the euthanasia registration forms sent in by reporting physicians.[14] The anonymous database was made available to us by the Committee.
Because of the anonymous nature of the notification procedure, it was impossible for the researchers to contact the reporting physicians for more in-depth information, or to match the reported cases to the corresponding death certificates. There were few missing data because the Committee generally contacts the reporting physician for further information when important data are missing (from the registration forms.)

We compared characteristics of all reported euthanasia cases with those of all deaths among residents of Flanders and Brussels in the corresponding period (January 1, 2003 – December 31, 2007). As death certificate data for Wallonia were not available for this period we had to rely on data from Flanders and Brussels which comprise about 65% of all deaths in Belgium and are expected to be suitable for comparison as about 83% of all the cases of euthanasia were reported by Dutch speaking physicians living in Flanders or Brussels, and comparison with the most recent available death certificate data for Wallonia (1999) do not show important differences with regard to age, sex, diagnosis, and place of death.

3.2.2 Measurements

The registration form was developed by the Committee and contains both open-ended and closed questions with pre-structured response categories.[14] Open-ended questions were encoded into categories by the Committee in the database that we received. Detailed information about the registration form and questions has been described elsewhere.[11]

3.2.3 Statistical analysis

Fisher's Exact test was used to compare categorical variables. P values that were less than or equal to 0.05 were considered to indicate statistical significance. Statistical calculations were performed with SPSS software version 16 or StatXact software.

3.3 Results

3.3.1 Frequency of reported euthanasia cases and comparison with all deaths

A total of 1917 euthanasia cases were reported between September 22, 2002 and December 31, 2007. The number of reported cases increased every year (Table 1). Of all cases, 83.3% was reported by Dutch-speaking physicians, 16.7% by French-speaking physicians (not in table).

Table 1 Frequency of reported cases of euthanasia in Belgium, 2002-2008

year	Number of deaths	number of reported cases of euthanasia	% of all deaths
2002*	105642	24	NA†
2003	103278	235	0,23
2004	101946	347	0,34
2005	103278	388	0,38
2006	101587	428	0,42
2007	100658	495	0,49
2008	NA	705	NA
Total		2622	

* Cases reported from September 22 up to and including December 31.
† NA denotes not available

Table 2 shows patient characteristics of all reported euthanasia cases in Belgium compared with all deaths in Flanders and Brussels. Men, younger patients and cancer patients were significantly overrepresented in euthanasia cases. Patients of 80 years or more were underrepresented in all places of death and among cancer and non-cancer patients (not in tables).

Table 2 Patient characteristics of all reported euthanasia cases 2002-2007 compared with all deaths in Belgium (Flanders and Brussels)*

Characteristic	Reported cases of euthanasia§ N=1917	All deaths* N=265597	P- value
	% of all cases		
Sex			**0.0046**
Men	52.7	49.5	
Women	47.3	50.5	
Age			**<0.001**
1-17	0.0	0.3	
18-39	3.0	2.0	
40-59	26.0	9.5	
60-79	53.1	37.9	
>79	17.9	50.2	
Diagnosis			**<0.001**
Cancer	82.5	23.5	
Other than cancer	17.5	76.5	
Place of death			**<0.001**
Hospital	51.7	52.3	
Home	42.2	22.4	
Care home	4.3	22.0	
Other	1.8	3.4	

Data presented are column percentages; p-values calculated with Fisher's Exact test. Percentages may not always amount to 100% because of rounding.
* Deaths statistics of persons older than one year from Flanders and Brussels (Belgium), 2003 to 2007.
§ Patient characteristics of reported euthanasia cases in 2008 not yet available

3.3.2 Characteristics of reported euthanasia cases

Characteristics of the decision and performance of euthanasia are displayed in table 3.
For patients who died in hospital the second physician was most often a specialist (69.7%) and for those who died at home or in a care home, a general practitioner (73.5% and 84.1% respectively). Palliative care physicians were

more often consulted for patients who died in hospital (15.7%) than for those who died at home (7.9%) or in a care home (4.9%) ($p<0.001$). Physicians in hospitals had consulted additional physicians (38.2% of cases) more often than those at home (29.6% of cases) or in a care home (31.7% of cases) ($p=0.002$) (not in table).

Furthermore, not all the variables from the registration form were included in the database and some variables were not registered for each year. Moreover, our data only offer insight into officially reported euthanasia cases. We cannot exclude the possibility that physicians do not always report their cases and that unreported cases differ from reported ones.[15] A possible social desirability bias also has to be taken into account, especially for variables relating to legal due care criteria.

The number of reported euthanasia cases has increased every year since legalisation. One explanation could be that the incidence of euthanasia has increased over the years. Belgium has known a strong increase in acceptance of euthanasia among the general population between 1981 and 1999 [16], a trend that may have continued after legalization in 2002, making it plausibly that patients increasingly see euthanasia as an acceptable end-of-life option for themselves. Physicians may also have become more willing to perform euthanasia in a climate where it is no longer illegal. Another explanation could be that physicians have become increasingly more willing to report euthanasia, likely in part because the Committee has never sent a reported case to the judicial authorities.[12-14]
The majority of euthanasia cases was reported in Dutch, while only 17% was reported by French-speaking physicians. To date, there are no empirical data on whether there are perhaps differing medical end-of-life practices in the Dutch-speaking and French-speaking communities, and/or whether there is a difference in willingness to report among physicians of both communities.

As was shown in other research [17] no evidence was found to support the fear that, once euthanasia is legalized, the lives of elderly patients would be more likely to be ended with assistance of a physician.[13,18,19] According to our findings, patients of 80 or older were underrepresented among euthanasia cases compared to all deaths even after controlling for diagnosis and place of death. The number of reported euthanasia cases in this age group also did not increase significantly over time. Older patients thus seem not to be at higher or increasing risk of euthanasia after legalization.

Table 3 Characteristics of the decision and performance of euthanasia (2002 - 2007)

	All cases (N=1917) % of all cases	
Type of request for euthanasia		
Current request	97.9	
Written advance euthanasia directive*	2.1	
Involvement of other caregivers		
Second independent physician consulted†	99.8	
Specialty of second independent physician		
Specialist		44.7
General practitioner		42.9
Palliative care physician‡		12.0
Unspecified		0.5
Third independent physician consulted (N=126) §	100	
Specialty of third independent physician		
Psychiatrist		60.3
Specialist		39.7
Additional physicians consulted (beyond legal requirement)		
At least 1 physician consulted	34.2	
1 physician	24.2	
2 physicians	6.8	
3 physicians	2.3	
4 physicians	0.7	
5 physicians	0.2	
6 physicians	0.1	
Extra palliative teams consulted¶ (not legally required)		
no palliative teams	65.5	
1 palliative team	32.3	
2 palliative teams	2.1	
3 palliative teams	0.1	
Drugs used to perform euthanasia**		
Barbiturate	34.3	
Barbiturate + neuromuscular relaxant	58.1	
Morphine alone or in conjunction with sedative	0.9	
Other, or unclear from registration form	6.7	

Data presented are column percentages. Percentages may not always amount to 100% because of rounding. NA denotes not applicable.

* Euthanasia based on a written advance euthanasia directive is only possible for patients who are in an irreversible coma.

† Information was missing for 3 cases. We cannot determine from our data whether these physicians were contacted by the Committee for further information.

‡ This percentage may be an underestimation as the question about the second physician' specialty is an open one and physicians were considered to have consulted a palliative care physician only when they explicitly mentioned this.

§ A third independent physician must be consulted only if the patient is not considered to be terminally ill, i.e. is not expected to die in the near future.[7,9-11] This physician should either be a psychiatrist or a specialist in the illness from which the patient suffers.

¶ Data are available for only 1714 of the reported euthanasia cases. In Belgium there are palliative homecare teams and palliative teams in hospitals. They consist of nurses, (a) physician(s), and a psychologist in hospital teams.
** Data are available for only 1699 of the reported euthanasia cases

Although physicians are required to consult only one other physician (or two where the patient is not terminally ill) physicians involved additional physicians or palliative care teams in a substantial number of cases. This may indicate that they are aware of the importance of consulting palliative care experts and offering available palliative care options for patients requesting to end their lives, which is consistent with findings that palliative care and euthanasia are often not seen as mutually exclusive alternatives by Belgian caregivers, but rather as integral aspects of good end-of-life care.[20] Another factor that may explain additional consultation is that the majority of Belgian hospitals permits euthanasia only if certain palliative care procedures are followed, in addition to those required by law.[23]

Physicians reported unbearable suffering in almost all euthanasia cases. Based on our data, however, we cannot determine whether the reported suffering had been target of intervention. Concerns that euthanasia requests are the result of low quality care or the absence of access to palliative care, are often expressed.[24-26] However, Belgium has a long tradition in palliative care provision integrated in mainstream healthcare and promulgated a law on palliative care almost simultaneously with the legalization of euthanasia, positing the right to palliative care for every patient and substantially increasing its funding.[27-29] Research conducted in Belgium has shown that euthanasia is not related to a lower use of palliative care and often occurs within the context of multidisciplinary care.[30] Nonetheless, our findings reconfirm the importance of not only pain and physical symptom relief at the end of life, but also of integrating psychosocial aspects in palliative care.[31,32]

In conclusion, our study gives insight into the medical practice of euthanasia in Belgium as reported since legalization in 2002. Based on these reported cases, we can conclude that euthanasia is most often chosen as a last resort at the end of life by younger patients and by patients with cancer. Developments over time do not show any indication to support the slippery slope hypothesis. Furthermore, requests for euthanasia from non-terminal patients, some suffering from non-somatic diseases, can and are being granted under the Belgian euthanasia law, albeit in small and not increasing numbers and under the same strict due care criteria as for terminally ill patients. Further research should focus on estimating the notification rate for euthanasia and should give attention to the unreported practice as well.

Table 4 Clinical characteristics according to whether the patient was terminally ill or not terminally ill* at the moment of the euthanasia (2002-2007)

	All reported cases N=1917	Terminally ill patients N= 1790 (93.4)	Non-terminally ill patients N=126 (6.6)	P-value
	% of all cases			
Diagnosis				**<0.001†**
Cancer	82.5	87.6	9.2	
Other than cancer	17.5	12.4	90.8	
Progressive neuromuscular disease	7.3	5.1	37.9	
Cardiovascular disease	2.4	2.0	8.9	
Non-malignant pulmonary disease	1.9	1.7	4.0	
Non-progressive neuromuscular disease	1	0.2	13.7	
AIDS	0.4	0.3	0.8	
Other	4.5‡	3.1	25.0	
Reported suffering§				
Physical suffering	95.6	96.0	89.7	**0.001**
Psychological suffering	68	66.5	89.7	**<0.001**
Physical and psychological suffering	64.7	63.7	79.4	**0.001**
Nature of reported physical suffering¶				
Pain	53.6	54.7	41	0.101
Cachexia, exhaustion	32.5	33.6	20.5	0.095
Dysphagia, vomiting, bowel obstruction	28.3	29.0	20.5	0.260
Dyspnoea	22.9	23.7	12.8	0.119
Severe wounds	5.4	5.9	0	0.119
Haemorrhage	2.8	3.1	0	0.269
Other	25.3	23.5	46.3	**0.001**
Nature of reported psychological suffering‡				
Loss of dignity/despair	42.5	42.0	47.5	0.503
Dependency	26.1	23.3	57.5	**<0.001**
Other	1.7	1.4	5.6	**0.028**

Data presented are column percentages; p- values calculated with Fisher's Exact test. Percentages may not always amount to 100% because of rounding.

* The euthanasia law makes a distinction between patients who are expected to die within the near future and patients who are not expected to die within the near future. Within the near

future is defined by the Federal Control and Evaluation Committee as dying within the next few months. Patients who were not expected to die within the near future were patients who were not expected to die within the next few months. It is the attending physician who evaluates the terminality of the patient's disease.
† p- value for cancer versus other than cancer.
‡ including, among others, 18 cases of neuropsychiatric disease: depression (n=5), Huntington's disease (n=5), Alzheimer's disease (n=5), Creutzfeldt-Jacob disease (n=1), vascular dementia (n=1), psychosis (n=1).[9-11]
§ For 22 patients no suffering was reported. Seven of these patients were comatose; for the remaining patients, information on the variables of suffering was missing. We could not determine whether the Committee had contacted the physicians for further information.
¶ Data for nature of physical and psychological suffering are only available for 499 of the reported euthanasia cases.

Table 5 Trends in characteristics of reported euthanasia cases in Belgium (2002 - 2007)

	2002*/ 2003 (N=259)	2004 (N=347)	2005 (N=388)	2006 (N=428)	2007 (N=495)	P-value
	% of all cases					
Patient characteristics						
Sex						0.780
Men	49.8	51.9	52.3	53.7	54.3	
Women	50.2	48.1	47.7	46.3	45.7	
Age						0.977
18-39	3.5	2.9	3.6	3.0	2.4	
39-79	79.9	79.0	77.1	78.7	80.4	
>79	16.6	18.2	19.3	18.2	17.2	
Diagnosis						0.597
Cancer	84.3	81.8	85.1	80.6	81.8	
Other than cancer	15.7	18.2	14.9	19.4	18.2	
Prognosis						0.637
Terminally ill	91.5	93.1	93.3	93.9	94.3	
Not terminal ill	8.5	6.9	6.7	6.1	5.7	
Place of death						0.299
Hospital	53.7	55.5	51.8	52.6	47.3	
Home	40.5	38.4	40.5	41.8	47.3	
Care home	4.6	4.3	5.4	3.0	4.2	
Other	1.2	1.7	2.3	2.6	1.2	
Characteristics of the decision						
Type of request for euthanasia						**0.021**
Current, voluntary, well-considered, repeated, and	99.6	98.6	97.9	96.0	98.2	

written request						
Written advance euthanasia directive	0.4	1.4	2.1	4.0	1.8	
Involvement of other caregivers						
Specialty of second independent consulted physician						**<0.001**
Specialist	47.1	42.2	46.9	45.6	42.6	
General practitioner	33.6	41.6	42.2	44.2	48.1	
Palliative care physician	19.3	14.7	10.9	10.0	8.7	
Unspecified	0.0	1.4	0.0	0.2	0.6	
Specialty of third independent physician† (N=126)						0.294
Psychiatrist	68.2	41.7	65.4	57.7	67.9	
Specialist	31.8	58.3	34.6	42.3	32.1	
Additional physician(s) consulted (beyond legal requirement)	39.0	38.0	34.0	28.0	34.4	**0.017**
Palliative team(s) ‡ consulted (not legally required)	33.9	33.7	31.4	32.5	39.4	0.110

Data presented are column percentages, except total numbers between brackets; p- values calculated with Fisher's Exact test. Percentages may not always amount to 100% because of rounding.

* Cases reported from September 22 up to and including December 31, 2002 (N=24).

† A third independent physician must be consulted only if the patient is not considered to be terminally ill, i.e. is not expected to die in the near future.[7, 9-11]

‡ Data are available for only 1714 of the reported euthanasia cases. In Belgium there are palliative homecare teams and palliative teams in hospitals. They consist of nurses, (a) physician(s), and a psychologist in hospital teams.

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CHAPTER 4
THE FIRST FIVE YEARS OF EUTHANASIA LEGISLATION IN BELGIUM AND THE NETHERLANDS DESCRIPTION AND COMPARISON OF CASES

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This paper has been submitted.

Abstract

The Netherlands and Belgium have legalised euthanasia in 2002. In this study we describe and compare reported cases of euthanasia and physician-assisted suicide in the first five years of legislation. The databases of the cases reported in Belgium and the Netherlands were made available by the review committees. We compared characteristics of all cases reported between September 2002-December 2007. In the Netherlands, 10319 cases were reported, in Belgium 1917. Gender and age distributions were similar in both countries. Most patients suffered from cancer (83-87%), but patients more often suffered from diseases of the nervous system in Belgium (8.3% vs. 3.9%).In the Netherlands, euthanasia more often occurred at home than in Belgium (81% vs 42%) where it occurred more often in hospital (52% vs 9%). In the Netherlands, all cases were based on the oral request of a competent patient. In Belgium, 2.1% of the cases was based on an advance directive. We conclude that countries or states debating legislation need to realise that the rules and procedures for euthanasia they would agree upon are likely to influence the practice that develops once the legislation is effected and what part of that practice is reported.

4.1 Introduction

In the Netherlands, there is a long history of de facto tolerance of euthanasia and physician-assisted suicide at the explicit request of the patient culminating in the enactment of the euthanasia law in 2002.[1] A first official reporting procedure was introduced in 1991. Belgium legalized euthanasia shortly after the Netherlands, in 2002. The legislation was largely based on the Dutch model, albeit without any preceding period of de facto tolerance and hence without gradually developed requirements and reporting procedures. The enactment was a fairly quick process compared to the Netherlands and it was largely politically driven, rather than urged by physician organisations as in the Netherlands. Both countries offer an exemption from punishment to physicians who have met certain requirements of due care, such as that the patient has to make a voluntary and well-considered request, based on unbearable suffering with no prospect of improvement. Both countries also have similar procedural requirements, such as mandatory a priori consultation of an other independent physician and a posteriori reporting to a committee for evaluation.[2,3]

There are also certain differences in the euthanasia legislations, eg only in Belgium a separate set of requirements exists for euthanasia based on an advance directive in persons in a persistent vegetative state or an irreversible coma. Unlike the Dutch law, the Belgian law makes a distinction between terminal and nonterminal patients, with two additional requirements for nonterminal patients: the physician must consult two independent physicians instead of just one, and there must be at least one month between the patient's explicit request for euthanasia and the performance. Only in the Netherlands, physician-assisted suicide is explicitly included in the euthanasia legislation.[2-4]
In this report, we compare the characteristics of cases of euthanasia and physician-assisted suicide reported in Belgium and the Netherlands in the first five years after enactment of the current legislation. By so doing, this study provides insight in whether and how differences in the rules and procedures for euthanasia lead to differences in the practice that develops once the legislation is effected.

4.2 Methods

The anonymized databases of the reported cases of euthanasia in Belgium and the Netherlands were made available by the review committees. We compared all characteristics that were available in the databases of both countries. We selected all cases reported between 22 September 2002 (date of first report in Belgium) and the end of 2007 in both databases.

We did not test statistical significance because the database is not a sample but comprehends all cases reported in this period.

4.3 Results

In the Netherlands, 10319 cases were reported between September 2002 and December 2007, in Belgium 1917. The characteristics of these cases are shown in Table 1.
Gender and age distributions were similar in both countries, although Belgian cases were more often persons of 80 years or older compared to the Dutch cases.
In both countries, the large majority of the patients suffered from cancer, although this majority was larger in the Netherlands than in Belgium (resp. 87% and 83%). Diseases of the nervous system are a larger portion of the cases in Belgium than in the Netherlands (8.3% vs. 3.9%).
The place of death was at home for 81% of the cases in the Netherlands, and 42% in Belgium. In Belgium, euthanasia more often took place in hospital (52% vs. 9% in the Netherlands).
In the Netherlands, all cases were based on the oral request of a competent patient. In Belgium 2.1% of the cases was based on an advance directive of a patient in an irreversible coma or a persistent vegetative state.
Physician-assisted suicide occurred more frequently in the Netherlands than in Belgium (7.8% vs. 1.0%).
In Belgium, all cases were considered careful, 0.2% of the cases in the Netherlands were referred to the judicial authorities for further investigation.

4.4 Discussion

This is the first comparison of cases of euthanasia and physician-assisted suicide reported in Belgium and the Netherlands in the first five years after enactment of the current legislation.
The absolute number of reported cases of euthanasia and physician-assisted suicide in the first 5 years of euthanasia legislation is more than 5 times higher in the Netherlands than in Belgium. This can only partly be explained by the 1.3 times higher number of annual deaths in the Netherlands. Additionally, in the Netherlands, probably partly as a result of the preceding period of de facto tolerance, the frequency of euthanasia was likely higher in the first years after the enactment of the euthanasia legislation. This difference in incidence rates seemed to have dissipated the first time they were empirically estimated several years after the enactment (1.8% of all deaths in the Netherlands in 2005, 1.9% in Flanders, Belgium in 2007).[5,6] Another additional explanation is that, in the

Table 1 All reported cases of euthanasia or assisted suicide by physicians in Belgium and the Netherlands from September 2002-December 2007*

	The Netherlands n=10319	Belgium n=1917
	% of all cases	
Gender patient		
Male	54	53
Female	46	47
Age patient (years)		
<20	0.2	0.1
20-39	3.2	2.9
40-59	31	26
60-79	53	53
≥80	12	18
Diagnosis		
Cancer	87	83
Cardiovascular disease	1.6	2.4
Lung disease (non-cancer)	2.8	1.9
Disease of nervous system	3.9	8.3
Other (incl combinations)	4.9	4.9
Place of death		
Home	81	42
Hospital	8.7	52
Other	10	6.1
Euthanasia based on an oral request or an advance directive		
Oral request	100	98
Advance directive	-	2.1
Type of help		
Euthanasia	91	99
Physician-assisted suicide	7.8	1.0
Combination	1.6	0.3
Decision of the Committee		
Careful	100	94
Careful with remarks	0.1	6.4
Uncareful, referral to a court of law	0.2	-

* Percentages do not always add up to 100% because of rounding

Netherlands, the reporting rate of euthanasia has been demonstrated to be higher than in Belgium (estimated at 80% in 2005 in the Netherlands, 53% in 2007 in Flanders, Belgium, rates first years after enactment are unknown).[7,8]

The comparison of the cases shows that there are similarities in the characteristics of the cases reported in the Netherlands and in Belgium with regard to diagnosis, age and gender. Reported euthanasia occurs in both

countries most often with cancer patients aged between 40-79 years. Also, in both countries, (almost) all reported cases are judged by the review committees to be performed according to the requirements of due care as set out in the legislation.

However, there are also some marked differences. Euthanasia occurred more often at home in the Netherlands than in Belgium and more often in hospital in Belgium than in the Netherlands. In Belgium, hospital deaths are in general more common than in the Netherlands; 52% of all deaths in Belgium [excl Wallonia, data not available for this region] vs. 34% in the Netherlands, especially in cancer patients who make up the majority of euthanasia cases in both countries (60% in Belgium vs. 31% in the Netherlands).[9] This does thus not fully explain why so many more Dutch euthanasia cases occurred at home. In both countries, people who receive euthanasia are more likely to die at home than the general population, but this is about two times more likely in Belgium, and three times more likely in the Netherlands. A possible explanation is that in the Netherlands general practitioners as "gatekeepers" have a more central role in the care of patients at the end of life than in Belgium.[10]

Smaller differences in the characteristics of the reported cases may be explained by three differences in the legislations of the Netherlands and Belgium. First, in Belgium there are more cases of euthanasia with patients who suffer from diseases of the nervous system. These patients often have a more chronic course of illness than cancer patients and are often considered to be nonterminally ill by the physician. The Belgian legislation has a distinction between terminal and nonterminal patients which makes explicit that euthanasia is allowed for such patients as well, which may contribute to more willingness to grant their euthanasia requests. In the Netherlands, euthanasia is also allowed in nonterminal patients, but this is not explicitly mentioned in the law, and 31% of the physicians is unsure or unaware of this.[11]

Second, in the Netherlands there are no reported cases of euthanasia based on an advance directive instead of an oral request. While euthanasia based on an advance directive in comatose or persistently vegetative patients is allowed in the Netherlands, the law does not explicitly provide for a specific procedure for these patients. The requirements for such cases are the same as for euthanasia in terminal patients, but how they should be interpreted is unclear. In Belgium, euthanasia based on a request in the form of an advance directive is explicitly regulated with clear separate requirements, which may explain the fact that– unlike in the Netherlands– such cases are performed and reported.

Third, that physician-assisted suicide occurs more frequently in the Netherlands than Belgium can be explained by the fact that the legislation in Belgium does

not explicitly include physician-assisted suicide, howbeit that it is considered by the Review Committee as a legal form of euthanasia if it is performed in the presence of a physician and in compliance with the due care requirements of the euthanasia law.[12] In the guidelines in the Netherlands, physician-assisted suicide is preferred over euthanasia if the patient is in good enough condition to be able to take the drugs.[13]

A limitation of this study is that only *reported* cases were compared. In the Netherlands, the large majority of cases is reported (estimated at 80%), but in Belgium only about half of all performed cases of euthanasia are reported (estimated at 53%).[7,8] In both countries, the main reason for not reporting seems to be that physicians are unaware of the fact their act constitutes euthanasia and should be reported. Where in reported cases medications are often used that clearly end the life of the patient (barbiturate followed by a neuromuscular relaxant), in unreported cases there is often less clarity of whether the medications have actually ended the life of the patient (high dosages of opioids or sedatives), and the physicians label their act more often as pain- and symptom treatment.[7,8] Therefore, the characteristics of the reported cases are not representative for all occurring cases, but especially for cases clearly considered as euthanasia by the physician.

In conclusion, the differences in the characteristics of the cases are most likely related to country differences in organisation of care, the process towards legalization and the idea among physicians of what kind of cases are allowed. Countries or states debating legislation need to realise that the rules and procedures for euthanasia they would agree upon are likely to influence the practice that develops once the legislation is effected and what part of that practice is reported.

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CHAPTER 5
EUTHANASIA IN PATIENTS DYING AT HOME IN BELGIUM: AN INTERVIEW STUDY ON PHYSICIANS' ADHERENCE TO LEGAL SAFEGUARDS

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Abstract

Background
Euthanasia became legal in Belgium in 2002. Physicians must adhere to legal due care requirements when performing euthanasia, eg consult a second physician and report each euthanasia case to the Federal Review Committee.
Aim
To study the adherence and non-adherence of GPs to legal due care requirements for euthanasia among patients dying at home in Belgium. To explore possible reasons for non- adherence.
Design, Setting, Methods
A mortality follow-back study was performed in 2005-2006 using the nationwide Belgian Sentinel Network of General Practitioners. Each week GPs reported medical end-of-life decisions taken in all non-sudden deaths of patients in their practice. We conducted GP interviews for each euthanasia case occurring at home.
Results
Interviews were conducted for nine of the 11 identified euthanasia cases. Requirements concerning the patient's medical condition were met in all cases. Procedural requirements such as consultation of a second physician were sometimes ignored. Euthanasia cases were least often reported (N=4) when the physician did not regard the decision as euthanasia, when only opioids were used to perform euthanasia, or when no second physician was consulted. Being unaware of which practices are regarded euthanasia, insufficient knowledge of the euthanasia law, and the fact that certain procedures are deemed burdensome seem to be factors that may contribute to explaining non-adherence to the euthanasia law.
Conclusions
Substantive legal due care requirements for euthanasia concerning the patient's request for euthanasia and medical situation were almost always met by GPs in euthanasia cases. Procedural consultation and reporting requirements were not always met.

6.1 Introduction

Medical end-of-life decisions, including euthanasia, are known to occur in several countries.[1,2] Belgium is, along with the Netherlands and Luxembourg, one of the few countries where euthanasia is legal.[3-6] It is often considered that while the secrecy in which it takes place in countries where it is illegal prevents the development of guidelines and standards for careful practice,[7,8] legalisation involves the creation of a regulatory system for societal control and the defining of a standard for careful medical practice.[3-6] Legalisation of euthanasia in Belgium included the establishment in the law of due care requirements (Box 1).[3] For any law on euthanasia to be successful it is a prerequisite that physicians who engage in the practice know and understand the due care requirements and adhere to them; to date, empirical information on adherence to the due care requirements of the euthanasia law in Belgium is lacking.

Box 1 Legal due care requirements for euthanasia in Belgium

Substantive requirements

- The patient must be 18 years or above
- The patient's request must be voluntary and not the result of any external pressure, well-considered and repeated, and must be put in writing.
- The patient must be in a condition of constant and unbearable physical or psychological suffering caused by illness or accident, for which medical treatment is unavailing and there is no possibility of improvement.

Procedural requirements

- The physician must inform the patient about his or her health condition and life expectancy, and together with the patient come to the belief that there is no reasonable alternative to the patient's situation
- The physician must consult a second independent physician about the serious and incurable character of the illness; he must consult a third independent physician if the patient is not terminally ill
- The physician must record the decision-making process in the patient's medical file
- The physician must report the case of euthanasia to the Federal Control and Evaluation Committee Euthanasia for review

Information about euthanasia practice in Belgium is principally based on the cases of euthanasia officially reported by physicians to the Federal Review Committee.[9-11] These data may not offer much insight into non-adherence as physicians risk criminal prosecution if the Federal Review Committee determines that the law has been breached. Physicians may therefore be inclined to report only those cases where due care has been taken, or present

their cases as compliant with the law.[7] While large-scale epidemiological studies conducted in Flanders (the Dutch- speaking part of Belgium),[1;12] provide information about the incidence of euthanasia and the decision-making process, they offer no in-depth insight into physicians' adherence and reasons for non-adherence to the legal due care requirements. After seven years of legalised euthanasia, it is thus still unknown how it is actually practiced by physicians in Belgium.

We therefore conducted in-depth interviews with general practitioners (GPs) shortly after a case of euthanasia and investigated how they had experienced it and had dealt with the due care requirements. We focused on cases in the home where the majority of euthanasia cases take place.[13] GPs have fewer guidelines for euthanasia[14] and less professional assistance available to them than physicians in hospitals, which makes investigating euthanasia by GPs in a home setting very relevant to identifying and understanding any problems they may encounter.
In this article we will answer the following research questions: (1) To what extent do GPs adhere to the legal due care requirements for euthanasia when performing euthanasia at a patient's home? (3) What are possible reasons for non- adherence? And, (3) how is euthanasia being performed and what drugs are used?

6.2 Methods

6.2.1 Study design, setting and participants

A large-scale mortality follow-back study was performed in 2005-2006 to monitor end-of-life care and decision-making in Belgium using the Sentinel Network of General Practitioners (SENTI-MELC study).[15] It concerned a quantitative registration study of deaths in GP practices within the Belgian Sentinel Network, a surveillance network founded in 1979 which has proved to be a reliable surveillance system for a wide variety of health-related epidemiological data [15-17] and which is representative of all Belgian GPs in terms of age, sex and region.[18] The study resulted in a robust representative sample of non-sudden deaths (n=1690) not restricted to a specific setting, age group or disease. The study protocol [15] has been published elsewhere.
GPs registered deaths weekly and immediately after they learned of them, using a standardised form.[15] From these we identified deceased patients who met the following inclusion criteria: aged one year or older at time of death, death did not occur "suddenly or totally unexpectedly" as judged by the GP and death occurred at home or in a care home. Based on these criteria, a large interview study was performed. The GPs involved in those cases meeting the inclusion

criteria were contacted by telephone and asked to participate in an interview. In this article we report only on the interviews involving home deaths registered by physicians as being the result of the "administration of a drug by someone other than the patient with the explicit intention of hastening the end of life on the explicit request of the patient" (ie euthanasia). No cases of euthanasia were reported in care homes.

6.2.2 Measurements

The interviews were face-to-face and semi-structured and included both closed-ended and open-ended questions. Answers to open-ended questions were written down verbatim. For all questions there was room to note additional qualitative information given by the GP.
Interview questions were based largely on existing questionnaires.[19-22] (see Box 2 for interview topics). The questionnaire was first developed in Dutch and then translated into French via backward-forward procedure.

6.2.3 Procedure

Strict procedures were used to preserve patient anonymity and physician confidentiality. Patient names were never identifiable to the interviewers or to other members of the research group: GPs used anonymous codes to refer to patients in the registration form and the interviewers gave them closed envelopes with patient information before the interview to make sure that the GP would give information about the correct patient. After the study the identity of the GP was permanently deleted from all files. This precluded risk of criminal prosecution in case of non-compliance with the law. GPs were informed of these precautions so they could speak freely. Several procedures were used to ensure data quality and avoid missing data. If the identity of a patient who died following the administration of a drug on their explicit request was left blank on the registration form, a follow-up letter was sent to the GP.

To preclude overburdening the GP, no more than one interview of one hour maximum per two months per GP was done. This did not exclude any euthanasia cases as no physician performed more than one euthanasia case within a 2-month period. In order to minimise recall bias the interview was arranged as soon as possible after identification. Data-entry was done with consistency, range and skip checks, and the answers to closed questions were entered twice.

Box 2 Interview topics assessed in this study

Questions on the patient's medical situation during the final months of life assessing:

- patient's main diagnosis
- symptom burden in the last week of life using an adapted version of the Memorial Symptom Assessment Scale Global Distress Index (MSAS-GDI)[32]

Questions on the patient's medical situation at the time the decision to end life on explicit patient request was made, assessing

- the extent to which the patient's medical situation was futile, without prospect of improvement
- the extent to which there was constant and unbearable physical and/or psychological suffering that could not be alleviated
- whether or not curative, life-prolonging or alternative palliative treatments could be considered that were not applied, and why these treatments were not applied

Questions on information, consultation and reporting of the euthanasia

- whether or not the physician had informed the patient about his health condition and life expectancy
- whether or not the physician had consulted (an)other physician(s), care givers, and relatives of the patient
- whether or not the physician reported the case to the Federal Review Committee, and what the reasons were for reporting or not reporting the case

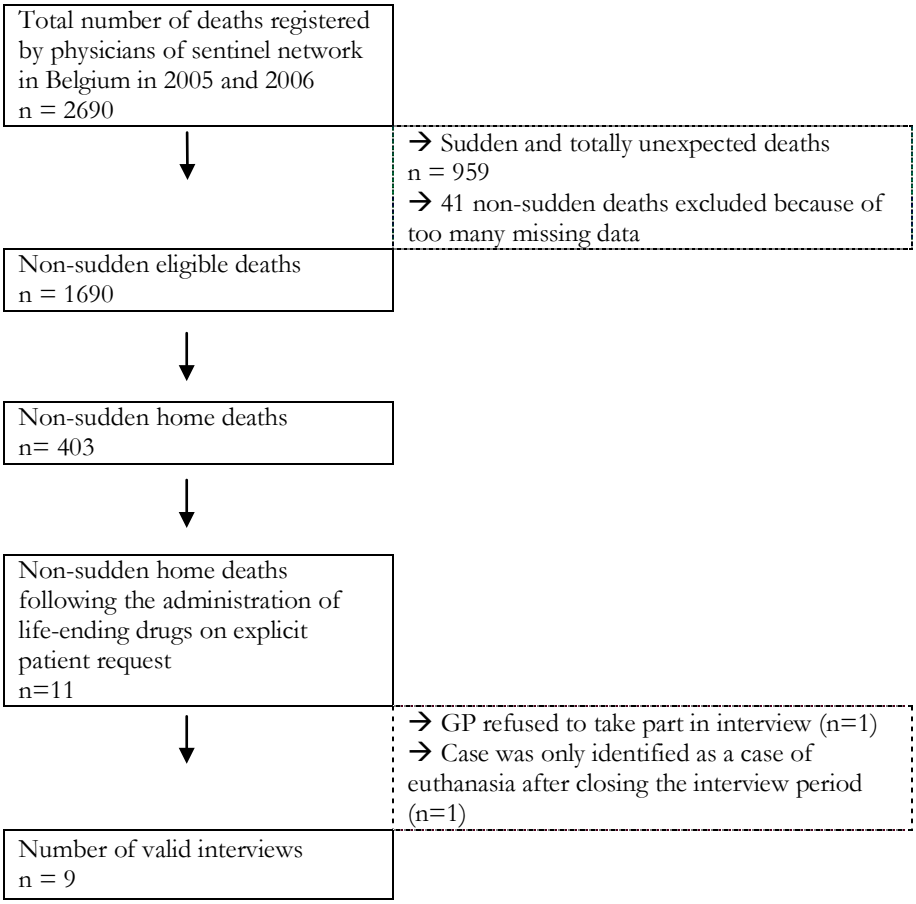
Questions on the performance of euthanasia assessing

- the drugs used to perform euthanasia
- the person who administered the drugs
- the time between the administration of the first drug and death
- technical problems during performance of euthanasia
- the life-shortening effect of the euthanasia

6.2.4 Analyses

All closed-ended questions were descriptively analysed. Answers to open-ended questions and additional information given by GPs were encoded into categories by two researchers and/or registered as quotes. These were interpreted by the authors together with the project committee. Socio-demographic patient information was retrieved from the registration study.

Figure 1 Selection of euthanasia cases



6.3 Results

Eleven euthanasia cases were registered in the two-year study period. One GP refused to be interviewed, and one GP could not be interviewed about a euthanasia case registered during the two-year study period because the registration form was only sent in by the GP after the interview period was already closed. In nine of the 11 cases, it was possible to interview the GP (figure 1). One of the interviewed physicians was responsible for two euthanasia cases (cases 1 and 8).

6.3.1 Demographic and clinical characteristics of the euthanasia cases

All nine patients who received euthanasia were adults, and none had a low level of education (table 1). None were estimated as being of low income and seven lived with a regular partner at the time of death. The main diagnosis was cancer (n=7).

6.3.2 Adherence to legal due care requirements for euthanasia

Substantive requirements

All patients had made a voluntary and well-considered request for euthanasia (Table 2). Eight had put their request in writing. One (case 8) had only made their request verbally and the GP did not find it necessary that they should do this in writing because, *"there was a relationship of trust between me, the patient and the family."* One patient (case 7) had made a request for euthanasia in writing but was persuaded by the GP to change this to a directive for palliative sedation. The GP indicated that they had "explicitly intended to end the patient's life by administering a drug upon the patient's request" which is the definition of euthanasia in this study, but did not label this act as euthanasia but as "terminal sedation with the explicit intention to hasten death." All patients were in a condition for which medical treatment was unavailing and there was no prospect of improvement. Most experienced lasting and unbearable physical and/or psychological suffering (n=8); one (case 4) was not suffering unbearably at the end of the decision-making process, but unbearable suffering was expected in the future.

Procedural requirements

In all cases the GP informed the patient about their health condition and life expectancy and in all cases they had together come to the conclusion that no more reasonable alternative treatments were possible. Sometimes the GP indicated that life-prolonging (n=3) or palliative treatments (n=4) were still possible, but they were not applied because the patient refused further treatment or did not want to prolong their life, or because patient or physician deemed the chance for improvement too small.

Table 1 Demographic and clinical characteristics of patients receiving euthanasia at home in Belgium

Demographic characteristics	**N=9**
Age	
1-17	0
18-64	4
65-79	3
>79	2
Sex	
Male	6
Female	3
Educational level	
Elementary or lower	1
Lower secondary	3
Higher secondary	1
Higher education / university	4
Estimated financial situation	
Low	0
Average	6
High	3
Living with regular partner at time of death	
Yes	7
No	2
Clinical characteristics	
Main diagnosis	
Cancer	7
Multiple sclerosis	1
Decompensated heart failure	1
Global Symptom Distress*	
Case 1	1.0
Case 2	2.0
Case 3	1.9
Case 4	1.2
Case 5	2.2
Case 6	1.1
Case 7	1.8
Case 8	1.0
Case 9	1.4

* Measured using the MSAS-GDI. The overall score per patient, representing global symptom distress,
is the mean of the item scores for four psychological symptoms (frequency items for worry, sad, irritable,
and nervous) and seven physical symptoms (distress items for lack of appetite, lack of energy, feeling drowsy, constipation, dry mouth, difficulty breathing, and pain).

Table 2 General practitioners' adherence to legal due care requirements for euthanasia

Case*	1	2	3	4	5	6	7	8	9	Total number of cases requirements met
Substantive requirements										
Patient is 18 years or above	+	+	+	+	+	+	+	+	+	**9**
Request										
Voluntary, and not result of any external pressure	+	+	+	+	+	+	+	+	+	**9**
Explicit	+	+	+	+	+	+	+	+	+	**9**
In writing	+	+	+	+	+	+	+	-	+	**8**
Well-considered	+	+	+	+	+	+	+	+	+	**9**
Repeated	+	+	+	+	+	+	+	+	+	**9**
Medical situation										
Constant and unbearable physical or psychological Suffering	+	+	+	-	+	+	+	+	+	**8**
Resulting from serious and incurable condition, caused by accident or illness	+	+	+	+	+	+	+	+	+	**9**
Hopeless / no prospect of improvement	+	+	+	+	+	+	+	+	+	**9**
Total number of substantive requirements met per case (max. 9)	**9**	**9**	**9**	**8**	**9**	**9**	**9**	**8**	**9**	
Procedural requirements										
Inform patient about health condition and life expectancy	+	+	+	+	+	+	+	+	+	**9**
Consultation										
Second physician consulted	+	+	+	+	+	+	-	-	-	**6**

Second physician was independent from patient and attending physician	+	-	+	+	+	-	NA	NA	NA	**4**
Report decision-making process in medical file	+	+	-	+	-	-	+	+	+	**6**
Report case to Federal Control and Evaluation Committee Euthanasia	+	+	+	+	+	-	-	-	-	**5**
Total number of procedural requirements met per case (max. 5)	**5**	**4**	**4**	**5**	**4**	**2**	**2**	**2**	**2**	
Total number of all requirements met per case (max. 14)	**14**	**13**	**13**	**13**	**13**	**11**	**11**	**10**	**11**	

+ means physician adhered to legal requirement; - means physician did not adhere to legal requirement; NA means "not applicable"

* Cases are ordered according to total number of all legal due care requirements met, with case 1 being the case in which most legal due care requirements were met.

In three cases the physician did not consult a second physician as required by law. One of these (case 7) did not find this sort of consultation necessary because he/she did not consider it a clear case of euthanasia. Another (case 9) did not consider a consultation because it *"was a case of euthanasia outside the euthanasia law. No lethal drug was used."* These two physicians, however, did consult other physicians who, while not performing the tasks required by the law, gave advice and information. One physician (case 8) did not consult another physician at all because he/she found the legal consultation procedure too burdensome and not useful, and believed it was "*up to the patient and physician alone to make the decision*." Nor did they consult any other caregivers, as opposed to those who consulted additional physicians (n=6) or caregivers like nurses and palliative teams (n=6) (data not in table).

In two out of the six cases the consulted physician was not independent from the attending physician and from the patient. In one case (case 2), the physician knew the consultant because they had followed classes in palliative care together; in another (case 6) the consultant was a friend of the attending physician (data not in table).

Five cases were reported to the Federal Review Committee. One physician who did not report gave as the reason that he/she had forgotten (case 6). Another said it was not a case of euthanasia but of terminal sedation with the intention of hastening death so did not have to be reported (case 7). The GP in case 8 did not report because he/she found the legal procedures too burdensome and because euthanasia was something between the patient and the physician alone. The physician in case 9 did not report it because he/she mistakenly thought that according to the law they should have waited for another fifteen days (data not in table).

6.3.3 Performance of euthanasia and drugs used

In six cases the physician performed euthanasia with a barbiturate, in combination with a neuromuscular relaxant (n=4) and/or benzodiazepines (n=2). In these cases the patient died within seconds or minutes after the first drug was administered. In one case (case 5) a barbiturate was administered after the patient had been terminally sedated for several days.

In two cases (cases 8 and 9) the GP used opioids with the explicit intention to hasten the patient's death. These patients died 24 and 48 hours respectively after the first drug was administered. In one case (case 7) the physician performed terminal sedation with the intention of hastening death using

opioids in conjunction with a barbiturate. The patient died three days after the process of terminal sedation was begun.

In most cases it was the GP who administered the final drug (n=8); in one case, however (case 9), it was a nurse. Some GPs reported having had technical problems during the performance. One physician (case 5) reported difficulties finding a vein; another (case 9) revealed that the patient had unexpectedly woken up between the administering of the two drugs.
The life-shortening effect of the euthanasia was mostly estimated to be less than one month (n=7). For two patients the life-shortening effect was estimated one to six months.

6.4 Discussion

6.4.1 Summary of main findings

We interviewed GPs in Belgium about concrete euthanasia cases in their practice and studied their adherence to legal due care requirements. In all cases, patients were in a condition for which medical treatment was unavailing and there was no prospect of improvement, and they had made an explicit, well-considered and repeated request for euthanasia. However, procedural requirements such as the consultation of a second physician or the reporting of euthanasia were ignored in some cases. Euthanasia was most often performed with barbiturates and/or neuromuscular relaxants. All but one physician labelled the end-of-life decision as euthanasia during the interview. Cases of euthanasia were least often reported to the Federal Review Committee when the physician did not consider them to be euthanasia, when they were performed with opioids, and when no legal consultation of another physician had taken place.

Table 3 Performance and life-shortening effect of euthanasia

Case*	**1**	**2**	**3**	**4**	**5**	**6**	**7**	**8**	**9**
Drugs used†	benzo-diazepine I.V. in 1 dosage + Barbitu-rate I.V. conti-nuous + narcotic antagonist I.V. conti-nuous	Barbitu-rate S.C.conti-nuous + neuro-muscular relaxant I.V. conti-nuous	Barbitu-rate I.V. in 1 dosage + neuro-muscular relaxant I.V. 1 dosage	benzo-diazepine I.V. in 1 dosage + Barbitu-Rate I.V. 1 dosage + Neuro-muscular relaxant I.V. 1 dosage	opioid S.C. conti-nuous + benzo-diazepine S.C. conti-nuous + Barbitu-rate‡ I.V. 1 dosage	Barbitu-rate I.V. 1 dosage + neuro-muscular relaxant I.V. 1 dosage	opioid T.D. conti-nuous + opioid I.V. with intervals + Barbitu-Rate I.V. conti-nuous	opioid S.C. with intervals + benzo-diazepine S.C. with intervals	Phenol-thiazine P.O 1 dosage + opioid T.D. conti-nuous + opioid S.C. conti-nuous
Person who administered the last drug	Physician	Physician	Physician	Physician	Physician	Physician	Nurse	Physician	Physician, nurse, family
Time between administration 1st drug and death	8 minutes	3 minutes	1 minute	1 minute	5 seconds	5 seconds	3 days	24 hours	48 hours
Technical problems during performance	None	None	None	None	Problem finding a vein in which to inject the drug	None	None	None	Patient woke up between administr ation of 2 drugs

Estimated life-shortening	1-6 months	1-4 weeks	1-7 days	1-4 weeks	1-4 weeks	1-6 months	1-7 days	1-4 weeks	1-7 days

* Same case order as in table 3

† S.C.= subcutaneous; I.V.= intravenous; T.D.= trans dermal; P.O.= per os.

‡ The fist drug to bring about death is in this case considered to be the barbiturate, as the other drugs were used to perform terminal sedation. The barbiturate was administered after the patient had been terminally sedated for 10 days. The patient died 5 seconds after the administration of the barbiturate.

6.4.2 Strengths and limitations of the study

Our study is the first to provide detailed information on concrete euthanasia cases in Belgium, taking place at home under the care of a GP. Because data were gathered through extensive face-to-face interviews with GPs, our study offers unique and thorough information on a practice about which little scientific and medical information exists to date. The cases presented were identified via a large-scale mortality follow-back study representative of all deaths in Belgium [15] and are therefore likely to be representative of euthanasia cases at home in Belgium. The reliability of the surveillance system from which GPs were selected for interview has been demonstrated elsewhere.[16-18] Recall bias was minimised as interviews were conducted within a few months of the GP registering the case. Our study also has some limitations. During the two-year study period only eleven cases of euthanasia were identified and an interview could be conducted in only nine of these. Our conclusions are thus based on a very small number of cases. Furthermore, our study is limited to euthanasia cases at home and cannot claim to be representative of euthanasia practice in hospitals or care homes. Future research could produce a sample from all care settings by identifying all euthanasia cases, including those in hospital, via death certificates and asking the involved physicians to be interviewed. Lastly, as interviews were conducted with GPs about their own adherence and non-adherence to the law we cannot exclude the possibility of social desirability bias.

6.4.3 Comparison with existing literature

In five out of the nine cases all or almost all legal due care requirements were met, indicating that the majority of physicians interviewed seemed to be aware of the importance of adhering to them in practice. However, in a few cases the procedural requirements concerning consultation of an independent physician and reporting of euthanasia were not met. Our study suggests a number of possible reasons for this: the self-labelling of the act, the drugs used, lack of knowledge about legal requirements, and attitudes towards the law and towards control.

Our study suggests that GPs are not always aware that they are engaging in an act that is legally regarded as euthanasia. When GPs are not aware that they are performing euthanasia they will not feel obliged to comply with the law. This finding is in accordance with findings from the Netherlands.[23] For example, when asked during the interview whether the case was one of euthanasia, one GP preferred to call it terminal sedation with the explicit intention of hastening death. However, as official guidelines state, when a patient requests their life to be ended and the physician performs terminal sedation or administers opioids

in doses higher than needed merely to alleviate pain or other symptoms and with an explicit intention of hastening death, the act equals euthanasia and the same legal due care requirements as for euthanasia apply.[24;25]

Although four physicians used barbiturates and/or neuromuscular relaxants to perform euthanasia,[26;27] some reported having used only opioids. Opioids are considered unsuitable for euthanasia because their effectiveness as a lethal drug is uncertain and there can be unwanted side-effects.[9;26;27] GPs who used opioids felt either very reluctant to perform euthanasia or had a negative opinion about certain procedures of the euthanasia law. They may have chosen opioids because these drugs are not normally associated with euthanasia. By disguising the end-of-life decision as normal medical practice, whether deliberately or not, they may have felt they have granted their patient's wish without in their eyes having performed real euthanasia and without having to comply with the euthanasia law. When cases of euthanasia were performed with opioids or other non-recommended drugs there was indeed considerably less adherence to the procedural legal due care requirements. At present, due care in the performance of euthanasia is not a legal requirement and uniform guidelines such as those that exist in the Netherlands [26] are lacking in Belgium.

Physicians also sometimes fail to comply with the law because of lack of knowledge about the due care requirements or uncertainty about how the legal requirements must be interpreted. However, there were also indications in the interviews that physicians sometimes fail to adhere to due care requirements because of a negative attitude towards aspects of the law; certain legal requirements, such as consultation and reporting, are deemed too burdensome or unnecessary.

In conclusion, this study found that while most of the GPs studied adhered to the substantive requirements, some demonstrated limited adherence to the procedural requirements.

6.4.4 Implications for clinical practice

Although legalisation of euthanasia in Belgium has changed it from a covert practice to a more societally-controlled one, legalisation alone does not seem sufficient to guarantee due care. It seems warranted that legalisation of euthanasia, rather than being a final destination, should be seen as a starting point for further debate about standards and guidelines for careful end-of-life practice and should go together with the proper education of, and provision of information to all physicians potentially involved. Incorporation in medical education, feedback from the Federal Review Committee to reporting GPs

about their medical actions, and accessible, adequate support for GPs who are confronted with an explicit request for euthanasia could help them in understanding which practices are regarded as euthanasia and could help overcome their limited knowledge of the euthanasia law.

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CHAPTER 6
REPORTING OF EUTHANASIA IN MEDICAL PRACTICE IN FLANDERS, BELGIUM: CROSS SECTIONAL ANALYSIS OF REPORTED AND UNREPORTED CASES

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Abstract

Objectives, design and setting

To estimate the rate of reporting of euthanasia cases to the Federal Control and Evaluation Committee and to compare the characteristics of reported and unreported cases of euthanasia. Cross sectional analysis in Flanders, Belgium.

Participants and main outcome measures

A stratified at random sample was drawn of people who died between 1 June 2007 and 30 November 2007. The certifying physician of each death was sent a questionnaire on end of life decision making in the death concerned. Outcome measures were the rate of euthanasia cases reported to the Federal Control and Evaluation Committee; physicians' reasons for not reporting cases of euthanasia; the relation between reporting and non-reporting and the characteristics of the physician and patient; the time by which life was shortened according to the physician; the labelling of the end of life decision by the physician involved; and differences in characteristics of due care between reported and unreported euthanasia cases.

Results

The survey response rate was 58.4% (3623/6202 eligible cases). The estimated total number of cases of euthanasia in Flanders in 2007 was 1040 (95% CI 970 to 1109), thus the incidence of euthanasia was estimated as 1.9% of all deaths (95% CI 1.6% to 2.3%). Approximately half (549/1040 (52.8%, 95% CI 43.9% to 60.5%)) of all estimated cases of euthanasia were reported to the Federal Control and Evaluation Committee. Physicians who perceived their case as euthanasia reported it in 93.1% (67/72) of cases. Cases of euthanasia were reported less often when the time by which life was shortened was less than one week compared with when the perceive life shortening was greater (37.3% *v* 74.1%;P<0.001). Unreported cases were generally dealt with less carefully: a written request for euthanasia was more often absent (87.7% *v* 17.6% verbal request only; P<0.001), other physicians and caregivers specialized in palliative care were consulted less often (54.6% *v* 97.5%; 33.0% *v* 63.9%; P<0.001 for both), the life ending act was more often performed with opioids or sedatives (92.1% *v* 4.4%; P<0.001), and the drugs were more often administered by a nurse (41.3% *v* 0.0%; P<0.001).

Conclusions

One out of two euthanasia cases is reported to the Federal Control and Evaluation Committee. Most non-reporting physicians do not perceive their act as euthanasia. Countries debating legalisation of euthanasia should simultaneously consider developing a policy facilitating the due care and reporting obligations of physicians.

5.1 Introduction

Medical end of life decisions including euthanasia, are known to occur in several countries.[1,2] Belgium is, along with the Netherlands and Luxembourg, one of the few places in the world where euthanasia is legal. Questions concerning efficient societal control over euthanasia and the prevention of abuse are at the forefront of the debate over euthanasia.[5,6] The secrecy in which euthanasia takes place in countries where it is illegal prevents the development of standards for careful practice and makes societal control difficult.[7,8] However, legalization of euthanasia usually involves defining a standard for careful medical practice and a system for societal control.[9-12] Due care criteria were embedded in the law when euthanasia was legalised in Belgium in 2002.[9,10] To make societal control over euthanasia possible, the law also requires physicians who perform euthanasia to report each case to the Federal Control and Evaluation Committee (review committee). This review committee determines whether or not the due care criteria of the law were respected and sends the case to the judicial authorities when irregularities are found.[9-13]

Since legalisation of euthanasia in Belgium, the Review committee has published three biennial reports covering all reported cases of euthanasia.[14-17] According to these documents, physicians who reported cases practised euthanasia carefully and in compliance with the law, and no cases of abuse have been found. However, concerns exist that only cases of euthanasia that are dealt with carefully are being reported.[18] Whether cases that are not reported to the official review system are dealt with equally carefully is uncertain.

In the Netherlands, surveys on end of life decisions have been conducted using a representative sample of death certificates to identify instances where a definition of euthanasia was met but the case was not reported to the authorities. These studies have shown that although reported and unreported cases of euthanasia did not differ according to patient characteristics and clinical conditions, physicians responsible for the unreported cases were less likely to have consulted a second physician or written a report on the decision.[19,20] The reporting rate in the Netherlands has gradually increased from 18% in 1990 to 80.2% in 2005, indicating a trend towards more societal control over the practice.[21] Most euthanasia cases that are not reported in the Netherlands are performed with opioids or sedatives and are often not perceived as euthanasia by the physicians themselves.[20,21]

The rate at which physicians in Belgium report cases of euthanasia is unknown, and differences between reported and unreported cases have not been investigated. In this large scale study of death certificates, we estimate the rate of reporting of euthanasia cases in Flanders, the Dutch speaking part of

Belgium, to the federal review committee. We investigate the relation between reporting and non-reporting of euthanasia and the characteristics of the physician and patient, the time by which life was shortened as estimated by the physician, and the labelling of the end of life decision by the physician involved. Finally, we study the reasons for non-reporting, and compare due care characteristics of reported and unreported cases.

5.2 Methods

5.2.1 Study design

We performed a study of death certificates in Flanders, Belgium, with the principal aim of estimating the incidence of medical end of life decisions with a possible or certain life shortening effect.[22] All deaths in Flanders must be reported to the proper government authorities and death certificates issued. By studying death certificates we were able to use death as the unit of measurement and reliably estimate the incidence and characteristics of end of life decisions.[23] A stratified at random sample of persons deceased in Flanders was drawn by the Flemish Agency for Care and Health, the central administration authority that handles death certificates. All deaths of Flemish residents aged 1 year or more that took place in Flanders between 1 June 2007 and 30 November 2007 were included. Deaths of Flemish persons that occurred outside of Flanders, deaths that occurred in Flanders of persons who were temporarily in Flanders but did not reside there on a permanent basis (mainly deaths by accident), and deaths of persons younger than 1 year were excluded.

To increase the reliability of the estimate of the total number of euthanasia cases, we oversampled cases where an end of life decision was more likely. Deaths were grouped into one of four strata according to the underlying cause of death on the death certificate and the corresponding probability of an end of life decision being made. Stratum one contained all deaths where an end of life decision was certain (that is, euthanasia indicated as the immediate cause of death); stratum two contained all deaths from neoplasms (international classification of diseases, 10th revision (ICD-10) codes C and D00-D48) where medical assistance in dying was probable; stratum three contained all deaths from causes where medical assistance in dying was possible (ICD-10 codes E, F, G, J, K, and N); and stratum four contained all deaths where medical assistance in dying was improbable. All deaths in stratum one were retained in the sample, whereas 50% of the deaths in stratum two, 25% in stratum three, and 12.5% in stratum four were included. This resulted in a sample of 6927 death certificates, which represents about 25% of all deaths in the sampling

period and about 12% of all deaths in the whole of 2007. Data were weighted afterwards to correct for the disproportionate stratification of the underlying causes of death.[22]

Every physician who had reported a death was sent a five page questionnaire. If the physician who received the questionnaire was not the main treating physician, he or she was asked to pass the questionnaire on to the treating physician. To guarantee total anonymity of physicians and patients, a lawyer was used as intermediary between responding physicians, researchers, and the Flemish Agency for Care and Health. We used the total design method to optimise the response rate.[24] An intensive follow-up mailing was conducted in cases of non-response.

Deaths where physician response to the questionnaire was impossible were excluded—for example, cases where the physician could not identify the patient on the basis of the information in the letter or did not have access to the patient file; cases where the certifying physician was not the treating physician for the patient in question; and cases where the identity of the treating physician was unknown.

Positive recommendations for the anonymity procedure and study protocol were obtained from the ethical review board of the University Hospital of the Vrije Universiteit Brussel, the ethics committee of the University Hospital of Ghent University, the Belgian National Disciplinary Board of Physicians, and the Belgian Federal Privacy Commission. The study design, sampling, and mailing procedure are described in detail elsewhere,22 and the first results of this study have previously been published.[25]

5.2.2 Questionnaire

The questionnaire focused on the characteristics of the end of life decision making that preceded the patient's death. Terms such as "euthanasia" were not used because they are subject to ambiguous and multidimensional definition. Instead, four key questions were used to more validly determine the types of decision in end of life care. The questions assessed whether the physician had taken any of the following measures: withholding or withdrawing medical treatment taking into account a possible life shortening effect; intensifying the alleviation of pain or other symptoms with a possible life shortening effect; withholding or withdrawing medical treatment with the explicit intention of hastening the patient's death; or administering, supplying, or prescribing drugs with the explicit intention of hastening the patient's death. The act was classified as euthanasia if the last of the four key questions was answered

affirmatively, the act was performed in response to an explicit request of the patient, and the physician or another person other than the patient himself or herself had administered the drug. This definition of euthanasia corresponds to the legal definitions of euthanasia in Belgium,[9] the Netherlands,[26] and Luxembourg,[27] and to the definition of euthanasia used by the European Association for Palliative Care in its official position statement on euthanasia.[28] For cases in which physicians responded affirmatively to more than one of the four key questions, the act that involved the most explicit intention with regard to the hastening of the patient's death was used to classify the act. When classifying cases of euthanasia, the administration of drugs prevailed over the withholding or withdrawing of medical treatment for cases in which there was no single most explicit intention.

The questionnaire also contained questions about the decision making process, the type of drugs used, and the life shortening effect of the act, as estimated by the physician. We also asked whether or not the physician had reported the case to the review committee, and, if appropriate, their reasons for non-reporting. Physicians were further asked to choose the term that they thought best described their act: alleviation of symptoms; non-treatment decision; palliative or terminal sedation; or euthanasia.

5.2.3 Analysis

To estimate the reporting rate for euthanasia in Flanders, two numbers are needed:
1) An estimate of the number of euthanasia cases reported to the review committee (numerator)
2) An estimate of the total number of euthanasia cases performed (denominator).
The survey of death certificates allowed us to estimate the total number of euthanasia cases in Flanders in 2007. To estimate the number of euthanasia cases reported to the review committee, we used the question that asked whether or not the physician had reported the case to the review committee.

The total number of euthanasia cases reported to the review committee in Belgium is actually known from the committee reports,[14-16] but we chose not to use the official data to calculate the reporting rate because they do not allow us to distinguish with certainty the euthanasia cases performed in Flanders from those performed in Brussels or Wallonia, the other two parts of Belgium. The classification "reported" or "unreported" was made using the question whether or not the physician had reported the case to the review committee. The total number of euthanasia cases and the total number of reported euthanasia cases

were estimated by weighting the sample for the disproportionate stratification procedure and for non-response bias with regard to age, sex, province, place, and cause of death, making the numbers representative for all deaths in Flanders in the study year. The weighting procedure was done in three steps. In the first step, the data were corrected for the disproportionate stratification procedure by assigning to the cases a weight that was the inverse of the sampling fraction of the stratum they had been assigned to We found proportionally less hospital deaths and more cancer deaths in the sample than in the population ($P<0.000$). To correct for this difference, in a second step the sample was weighted on the basis of place of death and cause of death by dividing the number of cases in the population by the sampled number for each combination of these characteristics. Finally, we found significant differences between responding physicians and non-responding physicians in the age, province, and place of death of their patients. We therefore calculated an additional weight by dividing the sampled number of cases by the responding number for every specific combination of these three variables. The different weights resulting from the three steps were combined into one overall weight. After this procedure no significant differences were found between the cases from responding physicians and the population for sex, age, province, place, and cause of death. The data are therefore representative of the entire population. The weighting procedure was done using binary logistic regression.

Differences in the distribution of characteristics between reported and unreported cases of euthanasia were tested by Fisher's Exact test. P values that were less than or equal to 0.05 were considered to indicate statistical significance. Statistical calculations were performed
with SPSS software version 16.0. Reliable multivariate models could not be made because of
multicollinearity.

5.3 Results

5.3.1 Reporting rate for euthanasia

The survey response rate was 58.4 (3623/6202 eligible cases). There were 6927 deaths in the sample, of which 725 were excluded because response for these cases was impossible. There were thus 6202 eligible deaths in the sample. The number of cases of euthanasia in the sample according to the death certificates was 137. Extrapolation on the basis of these 137 cases gave an estimated total number of cases of euthanasia in Flanders in 2007 of 1040 (95% CI 970 to 1109; table 1). The incidence of euthanasia in Flanders in 2007 was thus estimated as 1.9% of all deaths (95% CI 1.6% to 2.3%).[25] Approximately half

(549/1040 (52.8%, 95% CI 43.9% to 60.5%)) of euthanasia cases were reported to the review committee (that is, an estimated yearly number of 549, 95% CI 426 to 672).

Table 1 Reporting rates for euthanasia in Flanders, Belgium in 2007

	Number of cases	Rate
Estimated number of cases of euthanasia	137	--
Estimated number of reported cases of euthanasia	549	--
Estimated weighted total number of cases of euthanasia*	1040	1.9% (1.6% to 2.3%)†
Overall reporting rate for euthanasia‡		52.8% (43.9% to 60.5%)†
Reporting rates for euthanasia according to drug use‡§		
Recommended drugs¶	70	92.9% (84.3%-96.5%)
Non- recommended drugs**	61	4.8% (1.1%-16.9%)

*The estimated total rate of euthanasia was calculated by weighting for stratification and for patient and mortality characteristics of all deaths in 2007.25 The original number of euthanasia cases in the sample was 137. One case was missing data on the variable "reporting of end of life decision."
†Percent of all deaths in Flanders, Belgium, 2007.[25]
‡Weighted percentage.
§Five "missings" on the variable "drugs used for euthanasia."
¶Barbiturates, neuromuscular relaxants, or both.
**Opioids, benzodiazepines, or other drugs other than barbiturates or neuromuscular relaxants.

5.3.2 Reasons for non-reporting

The physicians who specified that they had not reported a case that the study defined as euthanasia (n=64 cases) were asked about the reasons for non-reporting. For 76.7% of these cases, physicians answered that they did not perceive their act as euthanasia, whereas for 17.9% they gave the reason that reporting is too much of an administrative burden, 11.9% that the legal due care requirements had possibly not all been met, and 9%that euthanasia is a private matter between physician and patient (8.7%). A small proportion (2.3%) did not report the case because of possible legal consequences (multiple answers were possible, not in tables).

5.3.3 Reporting of euthanasia according to characteristics of physician and patient, time by which life was shortened, and labelling of the end-of-life decision

General practitioners and specialists were equally likely to report their cases of euthanasia to the review committee (43/80 (53.8%) v 29/56 (51.8%); table 2).

We found no relation between reporting of euthanasia and the patient's sex, educational attainment, living situation, or place of death (table 2). However, in a bivariate analysis there was a significant relation between reporting of euthanasia and the patient's age, with deaths of patients aged 80 years or older reported significantly less often than deaths of younger patients (6/28 (21.4%) v 67/109 (61.5%); P=0.001). Cases were also reported less often when the time by which life was shortened was less than one week compared with when the life shortening effect was greater (27/73 (37.0%) v 42/57 (73.7%); P<0.001). These bivariate relations did not hold after controlling for labelling of the end of life decision (data not shown).

We asked all physicians who performed an act of euthanasia as defined in our study to choose the term that they thought best described the act. In 53.2% (72/136 (one case missing data on this variable)) of all cases, physicians chose the term "euthanasia." In the remaining cases the physicians chose a different label. The reporting rate for cases that were labelled "euthanasia" by the physician was 93.1%, whereas the reporting rate for cases labelled with a term other than euthanasia was much lower (7.8% overall). A large majority of the unreported cases (92.2%) involved acts of euthanasia as defined in our study but were not perceived or labelled as "euthanasia" by the physician (data not shown).

Table 2 Reporting of euthanasia according to characteristics of physician and patient, time by which life was shortened, and labelling of the end-of-life decision*

	All cases (n=137; weighted n)†	Reported cases (n=72)		P-value‡
		Weighted n	Weighted percentage of cases (95% CI)	
Physician characteristic				
Type of physician				
General practitioner	80	43	53.8 (41.5-65.4)	0.863
Specialist	56	29	51.8 (34.3-69.1)	
Patient characteristics				
Sex				
Male	83	43	51.8 (38.3-64.9)	0.727
Female	54	30	55.6 (39.3-70.0)	
Age				
18-49	12	8	66.7 (31.7-90.0)	**0.001**
50-64	37	23	62.2 (42.2-77.8)	
65-79	60	36	60.0 (45.3-72.8)	
≥80	28	6	21.4 (9.1-40.4)	
Educational attainment				
Primary school	20	7	35.0 (13.1-64.4)	0.309
Lower secondary	40	24	60.0 (41.2-75.8)	
Higher secondary or higher	37	21	58.8 (37.5-75.0)	
Unknown	41	21	51.2 (35.1-67.9)	
Living situation				
Alone	24	15	62.5 (40.6-80.5)	0.432
In private household	98	50	51.0 (39.1-63.0)	
In institution	10	4	40.0 (9.9-83.3)	
Place of death				
Home	66	37	56.1 (43.3-68.3)	0.874

Hospital	59	30	50.8 (34.1-67.6)	
Care home	5	2	40.0 (13.3-77.8)	
Other	6	3	50.0 (7.6-91.4)	
Diagnosis				
Malignant disease	111	58	52.3 (42.3-61.9)	**0.002§**
Cardiovascular disease	5	0	0.0 (0.0-0.0)	
Disease of the nervous system	7	6	85.7 (34.3-98.1)	
Disease of the respiratory system	6	2	33.3 (4.5-85.9)	
Other disease	5	5	100.0 (100-100)	
Shortening of life				
<24 hours	13	2	15.4 (4.8-40.1)	**<0.001**
1–7 days	60	25	41.7 (27.6-57.5)	
1– 4 weeks	35	21	60.0 (35.1-80.5)	
1-6 months	16	16	100.0 (100-100)	
>6 months	6	5	83.3 (44.0-98.8)	
Labelling of the end-of-life decision				
Euthanasia	72	67	93.1 (85.1-96.6)	**<0.001**
Palliative or terminal sedation	48	2	6.3 (1.5-21.6)	
Non-treatment decision	8	2	25.0 (1.8-78.6)	
Alleviation of symptoms	8	0	0.0 (0.0-30.1)	

*Percentages are row percentages. All percentages and total numbers are adjusted for stratification, and to patient/mortality characteristics of all deaths in 2007, which makes the percentages representative for all deaths in Flanders in 2007. Total numbers may not always amount to 137 due to rounding or missing values on variables. Percentages may not always amount to 100 due to rounding.

† 1 missing case on variable 'reporting of the end-of-life decision.'

‡ p- value for reported versus not reported.

§ $p<0.05$ using Fisher's Exact (Monte Carlo)

Table 3 Characteristics of due care of reported and unreported cases of euthanasia*

	All cases (n=137)‡		Reported cases (n=72)		Unreported cases (n=64)		
	Weighted n	weighted percentage of cases (95% CI)	Weighted n	weighted percentage of cases (95% CI)	Weighted n	weighted percentage of cases (95% CI)	P-value
Type of request euthanasia							**<0.001**
Verbal request only	68	50.0 (40.1-60.5)	13	17.(6 9.1-31.5)	55	87.7 (76.6-93.9)	
Written request only	9	6.6 (2.3-18.0)	7	9.3 (2.4-29.9)	2	3.7 (0.9-14.5)	
Verbal and written request	58	43.3 (33.5-53.1)	53	73.1 (56.8-84.9)	5	8.6 (3.9-18.0)	
Decision discussed with others‡	126	93.3 (80.2-97.8)	72	100 (100-100)	54	85.2 (63.0-95.1)	**0.001**
Other physicians	106	77.0 (66.2-85.7)	71	97.5 (88.1-99.5)	35	54.6 (38.7-69.6)	**<0.001**
Care-giver specialised in palliative Care	67	49.1 (39.2-59.6)	46	63.9 (49.6-76.2)	21	33.0 (21.3-47.2)	**<0.001**
Nursing staff	72	53.5 (42.8-63.3)	39	54.3 (40.5-67.5)	33	51.9 (36.6-66.9)	0.864
Relatives	106	77.5 (66.0-85.8)	57	78.4 (63.6-88.4)	49	76.2 (57.4-88.4)	0.841
Others	8	5.9 (2.9-11.9)	7	9.1 (4.2-18.7)	1	2.3 (0.3-15.0)	0.068
Drugs used for euthanasia							**<0.001**
Neuromuscular relaxant§	15	11.2 (6.5-18.9)	15	22.1 (12.8-35.0)	0		
Barbiturate¶	21	15.7 (10.5-23.2)	18	26.5 (16.6-38.5)	3	4.8 (1.8-13.0)	
Muscular relaxant +barbiturate**	34	26.6 (17.7-36.8)	32	47.1 (34.0-61.9)	2	3.2 (1.0-10.3)	
Opioids††	60	45.5 (35.5-56.4)	3	4.4 (1.0-15.4)	57	90.5 (80.2-94.8)	
Other drug	1	1.0 (0.2-4.1)	0		1	1.6 (0.5-8.3)	
Person who administered the drugs							**<0.001**
Physician	96	72.2 (60.8-81.0)	69	97.9 (86.5-99.7)	27	43.0 (29.0-58.3)	
Nurse	26	19.3 (11.7-30.4)	0		26	41.3 (26.3-57.5)	
Physician and nurse	9	7.4 (3.2-16.2)	1	2.1 (0.3-13.5)	8	13.4 (5.3-29.7)	

Physician and other person	2	1.2 (0.3-4.8)	0	2	2.6 (0.6-10.0)

*All percentages are adjusted for stratification and for patient and mortality characteristics of all deaths in 2007, which makes the percentages representative for all

deaths in Flanders in 2007.

†P<0.05, using Fisher's Exact (Monte Carlo).

‡One case was missing data on the variable "reporting of end of life decision." Total numbers may not always amount to 137 because of rounding or missing values on variables. Percentages may not always amount to 100 because of rounding.

§ Neuromuscular relaxant alone or in conjunction with benzodiazepine, opioids, or other drug other than barbiturate.

¶Barbiturate alone or in conjunction with benzodiazepine, opioids, or other drug other than muscle relaxant.

**Neuromuscular relaxant and barbiturate, alone or in conjunction with benzodiazepine, opioids, or other drug.

††Opioids alone or in conjunction with benzodiazepine or other drug other than barbiturate or neuromuscular relaxant.

5.3.4 Differences between reported and unreported cases

A verbal as well as a written request for euthanasia was present in 73.1% of all reported cases, whereas a legally required written request was absent in the majority of unreported cases (87.7% verbal request only; P<0.001; table 3). In reported cases, the decision to perform euthanasia was always discussed with others, which was not always the case in unreported cases (100% *v* 85.2%; P=0.001). Other physicians and care givers specialized in palliative care were consulted more often in reported cases than in unreported cases (97.5% *v* 54.6%; P<0.001 and 63.9% *v* 33.0%;P<0.001, respectively).No differences were found between reported and unreported cases for discussion of the decision to end the patient's life with nursing staff, relatives, or other persons (P=0.864, P=0.841, and P=0.068, respectively).

Reported cases of euthanasia were almost always performed with barbiturates, neuromuscular relaxants, or both (95.6%), whereas the majority of unreported cases (90.5%) were performed with other drugs, mainly opioids, sedatives, or both (P<0.001). However, in about half (52.7%) of the unreported cases in which opioids were used with the explicit goal of hastening death, physicians indicated that they did not administer a higher dose than necessary for pain and symptom alleviation. In reported cases of euthanasia, the drugs were almost always administered by a physician (97.7% of cases); in unreported cases, the drugs were often administered by a nurse alone (41.3%; P<0.001). When drugs were administered by a nurse alone, the agents used were always opioids or sedatives (not in tables).

5.4 Discussion

The reporting rate for euthanasia in Flanders in 2007 is estimated to be 52.8%. This means that only one out of two cases of actual euthanasia is reported to and reviewed by the Federal Control and Evaluation Committee, and one in two is not. The most important reason given by physicians for not reporting a case to the review committee was that the physician did not perceive the act to be euthanasia (76.7%).A large majority of the unreported cases (92.2%) were in fact acts of euthanasia as defined in our study but were not perceived or labelled as "euthanasia" by the physician involved. Unreported cases of euthanasia were generally dealt with less carefully than reported cases: a written request for euthanasia was absent more often; other physicians and care givers specialised in palliative care were consulted less often; the life ending act was more often performed with opioids, sedatives, or both; and the life ending drugs were more often administered by a nurse instead of a physician.

5.4.1 Strengths and limitations of study

This study is the first in Belgium to estimate the rate at which euthanasia is reported to the federal authorities and to study the differences between reported and unreported cases. We followed the same robust study design as in our previous studies [29] [30]: we drew a large representative sample of death certificates; used identical key questions; and applied the same mailing procedure to guarantee total anonymity for patients and physicians.

This study also has some limitations. The response rate was only 58%, so the possibility that the results could have been different had the response rate been higher cannot be excluded. We therefore urge caution in interpreting the results. Furthermore, the study is based on self reporting by physicians. It is possible that they did not remember all aspects of a case well, and we cannot exclude a social desirability bias, especially for the question of whether or not the physician had reported the case to the review committee. Unfortunately, because death certificate data for 2007 are not yet available for Wallonia, the French speaking part of Belgium, we could not estimate a reporting rate for the whole country. Our findings cannot be extrapolated to the French speaking part of Belgium, in particular because research has shown that end of life practices differ in the French speaking and the Flemish speaking regions and because there may be a difference in willingness to report cases of euthanasia owing to cultural differences.[31-32] A non-response bias cannot be completely excluded, although our non-response survey did not point to that possibility.

5.4.2 Study interpretation

Five years after the enactment of the euthanasia law in 2002, half of all euthanasia cases in Flanders were reported to the review committee. A similar reporting procedure exists in the Netherlands, where the current reporting rate is estimated at 80.2%.21 However, the Netherlands had already experienced two decades of relatively open euthanasia practice before euthanasia was officially legalised in 2002, and a reporting procedure has been in place since the early 1990s.[13,33] Compared to the Netherlands, bringing life ending acts into the open is a relatively new experience for physicians in Flanders (and in Belgium as a whole) because physicians have only been required to report cases since the enactment of the euthanasia law.[13,34] This may, at least in part, explain the lower reporting rate in Flanders compared with in the Netherlands. Another possible explanation could be that a higher number of unclear cases of euthanasia—in which opioids, sedatives, or both are used to hasten death instead of neuromuscular relaxants—occur in Flanders than in the Netherlands

and that there are more cases in which the estimated term of life shortening is small.[21] These less clear cut cases of euthanasia are often not perceived as euthanasia by the physicians and are consequently not being reported.

The considerable distance between the legal definition of euthanasia and the perception of the physician of whether an act was euthanasia could be explained by three possible coinciding hypotheses.
A first hypothesis suggests that when a patient requests that their life be ended and the physician in response disproportionally increases the opioid or sedative dose instead of administering neuromuscular relaxants, the distinction between euthanasia and normal compassionate intensification of symptom treatment is blurred. The confusion that may arise might mean that physicians do not perceive the life ending decision as euthanasia.[35] This would also explain why drugs are in these cases often administered by a nurse and not according to the requirements of the euthanasia law. This hypothesis is supported by findings from another study that has shown that some physicians see a "grey area," or continuum, between palliation and euthanasia and find that the distinctions between the two are not always clear cut.[35] The fact that some of the physicians in our study indicated that their use of opioids, sedatives, or both had the explicit intention of hastening death, yet at the same time indicated they had not used a higher dose than necessary to alleviate pain and other symptoms, may be an indication of the confusion that can arise in these situations. Although the physicians in our study had the intention of hastening death and believed that death was the result of using these drugs, it is possible that some may have overestimated the actual life shortening effect of the drugs they administered.

A second proposed hypothesis is one of reducing cognitive dissonance. Some physicians may on the one hand feel reluctant to perform euthanasia or follow the requirements of the euthanasia law, while on the other hand want to help the patient who requests euthanasia. To reduce this cognitive dissonance, they may choose to use opioids or sedatives because these drugs are not normally associated with euthanasia. Research has also shown that this kind of life ending practice might be more psychologically acceptable to physicians than euthanasia by bolus injection.[36] By disguising the end of life decision as normal medical practice, whether deliberately or not, physicians might feel they have granted their patient's wish without in their eyes having performed real euthanasia and without having to comply with the euthanasia law. Opioids and sedatives are used to perform euthanasia more often in patients older than 80 than in younger patients, which may indicate that physicians are perhaps more reluctant to perform euthanasia in elderly patients. Research from the Netherlands has shown that requests for euthanasia from older patients are often refused.[37] There are strong positive associations with refusing a request

where the patient is not fully competent and where there is a lesser degree of unbearable and hopeless suffering.[37] It is possible that physicians find that older patients' requests or suffering are not explicit enough to merit what is in their eyes real euthanasia by bolus injection.

A third hypothesis has to do with perceived time pressure. Our results indicate that unreported cases involved a shorter period by which life was shortened. It is plausible that, in cases in which the patient is obviously in a lot of pain and then requests euthanasia, the physician may feel under pressure to help the patient as soon as possible. He or she could then begin the process of euthanasia, but this process can be experienced as too time consuming or burdensome. The physician may in these circumstances prefer to use opioids or sedatives because these drugs are more readily available and there is less control over their distribution than with neuromuscular relaxants. By disguising euthanasia as pain alleviation, physicians can proceed with the euthanasia process without having to comply with the stringent, and in their perception time consuming, procedures of the euthanasia law.

We found a strong relation between a priori consultation of other physicians and the reporting of euthanasia. Consultation occurred in almost all reported cases, whereas it occurred in only half of all unreported cases. This association was also found in the Netherlands, [38,39] where the most important reason for not consulting was that the physician did not intend to report the case. Physicians who intend to report a case seem to consult another physician and comply with the other requirements of the law, whereas physicians who do not intend to report a case appear to consult a physician only when they feel the need for the opinion of a colleague.[39] In the Netherlands, the availability of a service of expert consultants has had a positive influence on the reporting rate of euthanasia.[38] A similar service was developed in Flanders,[40-42] and it is likely that such services, in increasing physicians' knowledge of euthanasia, may help increase the reporting rate.

5.4.3 Conclusions and policy implications

The quality of medical practice at the end of life needs monitoring in any kind of society, and certainly in countries that have legalised euthanasia. To provide better societal control over euthanasia and safeguard the quality of the practice, it is necessary that all cases of euthanasia are reported. The transparency in reporting that was envisaged by the architects of the euthanasia law in Belgium extends especially to those cases in which the time by which life is shortened is greater than one week and to those cases in which it is more certain that life is shortened by the drugs administered. However, this study estimated that in

2007 only half of all cases of euthanasia in Flanders and around three in four where life was shortened by more than one week were reported to the review committee.

As such legalisation alone does not seem sufficient to reach the goal of transparency ("total" or a 100% transparency seems to be a rather utopian ideal) and to guarantee the careful practice of euthanasia. It seems warranted that a policy be developed to facilitate physicians in complying correctly with a request for euthanasia, including their obligation to report. Education in medical schools and adequate support for treating physicians who are confronted with an explicit request for euthanasia will be pivotal in reaching that goal.

The possibility of societal control over the euthanasia practice is an important prerequisite for effective euthanasia legislation. By estimating the reporting rate for euthanasia in a country that has legalised the practice and by investigating reasons for non-reporting, our study offers valuable data driven information that can inform the debates about the legalisation of euthanasia that are currently going on in the United Kingdom and in many other countries.

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CHAPTER 7
THE LABELLING AND REPORTING OF EUTHANASIA BY BELGIAN PHYSICIANS: A STUDY OF HYPOTHETICAL CASES

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Abstract

Background
Belgium legalized euthanasia in 2002. Physicians must report each euthanasia case to the Federal Control and Evaluation Committee. This study examines which end-of-life decisions (ELDs) Belgian physicians label 'euthanasia', which ELDs they think should be reported and the physician characteristics associated with correct 20 labelling of euthanasia cases, the awareness that they should be reported and the reporting of them.

Methods
Five hypothetical cases of ELDs: intensified pain alleviation, palliative/terminal sedation, euthanasia with neuromuscular relaxants, euthanasia with morphine and life-ending without patient request were presented in a cross-sectional survey of 914 physicians in Belgium in 2009.

Results
About 19% of physicians did not label a euthanasia case with neuromuscular relaxants 'euthanasia', 27% 25 did not know that it should be reported. Most physicians labelled a euthanasia case with morphine 'intensification of pain and symptom treatment' (39%) or 'palliative/terminal sedation' (37%); 21% of physicians labelled this case 'euthanasia'. Cases describing other ELDs were sometimes also labeled 'euthanasia'. Factors associated with a higher likelihood of labelling a euthanasia case correctly were: living in Flanders, being informed about the euthanasia law and having a positive attitude towards 30 societal control over euthanasia. Whether a physician correctly labelled the euthanasia cases strongly determined their reporting knowledge and intentions.

Conclusion
There is no consensus among physicians about the labelling of euthanasia and other ELDs, and about which cases must be reported. Mislabelling of ELDs could impede societal control over euthanasia. The provision of better information to physicians appears to be necessary.

7.1 Introduction

Medical end-of-life decisions that possibly influence the remaining life-span frequently precede dying in many countries.[1-3] They include decisions to withhold or withdraw potentially life-prolonging treatments, to alleviate pain or other symptoms with a possible life-shortening side effect, to administer life-ending drugs without explicit patient request, and to perform physician-assisted suicide or euthanasia. The decision to perform palliative or terminal sedation can also be made, which is the administration of drugs to keep a patient continuously in deep sedation or coma until death,[4,5] Euthanasia is legal only in the Netherlands, Luxembourg and Belgium.[6-8] Since 2002, physicians in Belgium may under strict legally defined circumstances administer life-ending drugs at the explicit request of a patient.[8] The practice of euthanasia embraced 1.9% of all deaths in Flanders, Belgium, in 2007.[9] To enable societal control over euthanasia, physicians must report each euthanasia case to the Federal Control and Evaluation Committee (Review Committee) which determines whether the physician has complied with the requirements of the law.[8]

A post-mortem survey conducted in Flanders (the Dutch-speaking part of Belgium) suggested that about half of all euthanasia cases are not being reported.[10] The main reason euthanasia cases were not being reported was that many cases were not labelled as euthanasia by the physicians involved in the decision.[10] A similar reason for not reporting euthanasia cases was found in the Netherlands.[11-13] In actual practice the dividing lines between different end-of-life decisions, such as between the alleviation of pain and symptoms and euthanasia may not always be easy to define.[11,14-16] Euthanasia is considered to be 'the administration of life-ending drugs by a physician with the explicit intention of ending a patient's life, at the latter's explicit request.'[8, 17] The death of the patient must also be the result of the administration of the drugs.[8] Not all physicians may be aware of this definition, and even if they are, its interpretation can be complex for physicians who are for instance uncertain about the actual effect of giving certain drugs on the ending of life.[18] For euthanasia, the administration of barbiturates followed by a neuromuscular relaxant is advised[19,20] because they ensure a peaceful and certain death. In practice physicians also perform euthanasia with opioids[13,21], howbeit that opioids are advised against for euthanasia because they have an uncertain life-shortening effect and can have unpleasant side-effects.[19,20] When opioids are used with the intention to end life, the actual life-ending effect may thus not always be very clear for the physician.[18] Non-reporting may not only be caused by confused definitions, but also by other factors, such as a physician's unwillingness to report euthanasia cases, for example out of fear of criminal prosecution or because the reporting procedure is perceived as too burdensome.

If euthanasia is not labelled as euthanasia, this would be problematic as it could hamper effective societal control over euthanasia practice.
Mislabelling other end-of-life decisions as euthanasia would also be problematic because it could make physicians hesitant to apply certain end-of-life interventions as they might be afraid that they are performing euthanasia.
How physicians label different end-of-life decisions, which of these decisions they think must be reported as euthanasia, which decisions they would report themselves, and the multitude of personal, attitudinal and knowledge determinants of correct labelling of euthanasia, and of reporting and non-reporting of euthanasia, have not been investigated in Belgium. Insight into those issues can contribute to the further understanding of euthanasia practice in Belgium and to the debate about the prospect of efficient societal control over euthanasia in countries which are debating the legalization of the practice.
The aim of this article is to answer the following research questions:

1) Which end-of-life decisions do physicians in Belgium think are euthanasia and should be reported, and which end-of-life decisions would they report themselves?
2) Which personal, attitudinal and knowledge variables predict whether physicians label a euthanasia case as euthanasia, know euthanasia must be reported and would report it themselves?

7.2 Methods

7.2.1 Study design

In 2009 we sent a questionnaire to a representative sample of 3,006 physicians registered as working in Belgium, who had graduated in their specialty at least 12 months before the sample was drawn and were likely to be involved in the care of dying patients on the basis of their specialty: general practitioners, anesthesiologists, gynecologists, internists (including oncologists), neurologists, pulmonologists, neuro-psychiatrists, psychiatrists, cardiologists, radiotherapists, and surgeons were included. The sample was stratified for province and speciality; for each of the ten provinces a random proportional sample was drawn within each speciality.

A lawyer was involved as intermediary between responding physicians and researchers in the mailing procedure to guarantee the anonymity of the physicians. According to the Total Design Method an intensive follow-up mailing in case of non-response was performed with up to three reminders.[22]
Finally, non-responders were sent a one-page questionnaire to assess non-response bias. Alongside reasons for not participating to the survey, questions

were asked about two key items in the survey, the physician's acceptance of euthanasia and whether or not he/she had ever received a request for euthanasia.

7.2.2 Measurement instrument

The pre-structured questionnaire drew partly on questionnaires previously used.[23,24] The questionnaire was developed in Dutch and forward-backward translated into French to avoid differences due to language. Questions were asked about the physician's socio-demographics, work-related characteristics and attitudes and practices concerning euthanasia. Physicians were presented with five hypothetical cases of a patient in the final stage of a terminal disease (see Box 1). In each case (except in case 5 where the patient is unconscious), the patient explicitly asks the physician to end his/her life. This factor was kept constant as we especially wanted to focus on the act that the physician performs in response to such a request for life-ending. The scenario varied between the drugs administered, the mode of administration, and the effect of the administration of the act, thus covering the different types of end-of-life decisions. As we were interested in how physicians label a medical decision based on objective facts, we did not explicitly mention the intention of the physician because intentions are known to be multilayered and ambiguous. Using the intention of the physician would also have been too influential as to the correct labeling of the cases.
For each case we asked the physician which label best describes the act (euthanasia, palliative/terminal sedation, life-ending without explicit request, intensification of pain and symptom treatment, other), whether they thought it conceivable that they would perform a similar act themselves, whether the act should be reported to the Review Committee, and whether they would report the act themselves. In order to select relevant and realistic cases, a variety of cases was presented to several experts in the field of palliative care. We selected cases based on suggestions from the experts and on the literature.

7.2.3 Statistical analysis

Significant differences between response population and total sample were found for region but not for specialism. A weighting factor was used to correct for this response bias by region, making the data representative for all physicians in the sample.
Differences between physicians' answers on the different hypothetical cases were tested by Fisher's Exact test. P values that were less than or equal to 0.05 were considered to indicate statistical significance. Multivariate logistic

Box 1 Description of hypothetical cases presented to physicians in the questionnaire

Case 1 Intensification of pain and symptom treatment
Patient is 73 years old and has an inoperable oesophageal carcinoma with extensive metastasis. Patient is weary and has pain over the whole body. Patient has only a few more days to live. Patient's pain is treated with morphine patches, but they alleviate insufficiently. Patient has several times explicitly requested the physician to end his/her life. It is decided to administer morphine via a pump. The dose is gradually and proportionally raised. Patient dies 10 hours after the morphine pump was started.

Case 2 Palliative/terminal sedation
Patient is 73 years old and has an inoperable oesophageal carcinoma with extensive metastasis. Patient is weary and has pain over the whole body. Patient has only a few more days to live. A morphine pump alleviates the pain insufficiently. Patient has several times explicitly requested the physician to end his/her life. It is decided to administer midazolam until death and to forgo fluids and nutrition. Patient soon becomes comatose and dies three days after midazolam was started.

Case 3 Euthanasia 2: using morphine
Patient is 73 year old and has an inoperable oesophageal carcinoma with extensive metastasis. Patient is weary and has pain over the whole body. Patient has only a few more days to live. Patient has several times explicitly requested the physician to end his/her life. It is decided to administer morphine via infusion. The dose is doubled every 12 hours. In addition, valium is added to the infusion. Patient dies 24 hours after the infusion is started.

Case 4 Euthanasia 1: using a neuromuscular relaxant
Patient is 73 year old and has an inoperable oesophageal carcinoma with extensive metastasis. Patient is weary and has pain over the whole body. Patient has only a few more days to live. A morphine pump alleviates the pain insufficiently. Patient has several times explicitly requested the physician to end his/her life. At an agreed timing the physician administers a sleep-inducing drug and subsequently a neuromuscular relaxant. Patient dies minutes after administration of the neuromuscular relaxant.

Case description and underlining are presented the same as in the original questionnaire, save for the case titles.

regression was performed to estimate associations between a physician's characteristics and their labeling or reporting of euthanasia cases. Odds ratios and 95% confidence intervals are presented. The analyses were performed using SPSS 16.0 (SPSS Inc., Chicago, IL) and StatXact 6.

7.3 Results

7.3.1 Response rate and response bias

Of the 3,006 questionnaires sent, the non-response study found out that response was impossible for 223 respondents: 149 of those physicians did not receive the questionnaire, 1 physician was ill, 1 was deceased and 72 were no longer active as a physician or worked in a specialism that was not included in our study.
Of the remaining 2,783 questionnaires, 914 were returned. Of the non-responders, 583 replied to the non-response questionnaire. Not being involved in the care of dying patients and never responding to questionnaires were the main reasons for non-response. Those indicating they no longer worked as physicians (N=32) or had not received the questionnaire (N= 25) were subtracted from the denominator. Thus, the response rate of the study was 34%.
Non-responders were somewhat less likely to agree that euthanasia is acceptable (87.4% versus 93.0%, p=0.001) and were more neutral toward the statement than responders (8.8% versus 4.0%, p=0.001). No significant difference between responders and non-responders was found for the question whether or not the physician had ever received a request for euthanasia (48.3% of responders versus 46.0% of non-responders ever received a request; p=0.405).

7.3.2 Characteristics of responding physicians

Sixty four percent of responding physicians were men, 49% were Roman Catholic, 62% were general practitioners, 61% had more than twenty years experience as a physician, 48% had received training in palliative care, and 19% had cared for more than ten terminal patients in the last year (table 1).

7.3.3 Labelling and reporting of end-of-life decisions

Eighty one percent of physicians labelled the case in which the physician administers a sleep-inducing drug and a neuromuscular relaxant at the explicit request of the patient as 'euthanasia'; 9% labeled this case as 'palliative/terminal sedation' (table 2). The case in which the physician ends the patient's life using morphine was labelled as 'euthanasia' by 21% of physicians. This case was more often labelled as 'intensification of pain and symptom treatment' (39%) or as 'palliative/terminal sedation' (37%).

Table 1 Characteristics of the studied physicians

Characteristic	N= 914	%
Socio-demographics		
Sex		
Men	576	63.5
Women	323	35.6
Age		
35 or younger	110	12.4
36-50	323	36.7
51-65	398	45.1
66 or older	51	5.8
Religious affiliation/philosophy of life		
Roman Catholic	428	49.1
Other denomination	21	2.4
Religious, but no specific denomination	104	12.0
Humanist	163	18.7
Not religious	155	17.8
Region		
Flanders	480	52.8
Wallonia	305	33.6
Brussels	123	13.6
Work-related characteristics and experiences		
Speciality		
General practitioner	561	61.8
Clinical specialist	347	38.2
Years experience as physician		
10 or less	148	16.6
11-20	202	22.6
21-30	287	32.1
31-40	216	24.1
>40	40	4.5
Training in palliative care		
Yes*	433	48.1
At medical school	133	30.4
In postgraduate education	375	85.8
Other training	46	10.5
Member of palliative team/service		
Yes	47	5.3
Number of terminal patients cared for in the last 12 Months		
0	202	24.5
1-9	463	56.2
≥10	160	19.4

* More than 1 answer possible

The acts described in the other cases were also sometimes labelled as 'euthanasia', but less frequently so (between 6 and 11%).
The case in which the physician gradually and proportionally raised the dose of morphine was most often labelled as 'intensified pain alleviation'; the case in which the physician administers midazolam until death was labelled as 'palliative/terminal sedation' by 63% of the physicians. The case in which the physician ends the life of a comatose patient by disproportionally raising the dose of morphine and adding valium to the infusion was labelled as 'intensification of pain and symptom treatment' by 43% of the physicians and less often as 'life-ending without patient request' (17%).
For all cases which were labelled as 'euthanasia' or 'life-ending without explicit request', the physicians were less likely to find it conceivable that they would perform a similar act themselves than for cases which they labelled differently ($p<0.001$) (not in tables).

Seventy three percent of physicians were aware that the case in which the physician administers a sleep-inducing drug and a neuromuscular relaxant at the explicit request of the patient had to be reported to the Review Committee (table 2). Twenty two percent of physicians who did not label this case as 'euthanasia' were aware that the case had to be reported, while fourteen percent of those who did label the case as 'euthanasia' said it did not have to be reported or that they did not know whether the case had to be reported or not. Sixty eight percent of physicians indicated that they would report the case themselves. Fifty eight percent of those who indicated that they would not report the case themselves did find it conceivable that they would perform a similar act themselves (not in tables). Physicians who labelled the other cases as 'euthanasia' indicated most of the time that they would also report the case.

7.3.4 Factors associated with correct labelling of euthanasia cases

In a multivariate logistic regression analysis using the case in which the patient explicitly requests that their life be ended and the physician administers a sleep-inducing drug and subsequently a neuromuscular relaxant, factors associated with a higher likelihood of labelling this case correctly as 'euthanasia' were living in Flanders (OR 2.69), being sufficiently informed about the euthanasia law (OR 1.69), and having a positive attitude towards societal control over euthanasia (OR 1.74) (table 3).
Using the case in which the physician ended the patient's life at his/her request using morphine, factors associated with a higher likelihood of labelling this case as 'euthanasia' were being against euthanasia (OR 1.87), and not having cared for terminal patients in the last year (OR 1.00).

Table 2 Differences between cases according to physicians' willingness to report the case and their labelling of the act

	Case 1 Intensified pain alleviation	Case 2 Palliative/ terminal sedation	Case 3 Euthanasia 2 (with morphine)	Case 4 Euthanasia 1	Case 5 Life-ending without request	p-value
Which label describes best the act that the physician performs?						<0.001
Euthanasia	10.7	9.7	20.5	80.9	6.2	
Palliative/terminal sedation	24.0	73.2	37.2	9.1	32.4	
Life-ending without explicit request	1.1	2.3	1.8	3.3	16.6	
Intensification of pain and symptom treatment	63.4	13.1	38.5	4.9	43.3	
Other	0.9	1.7	2.0	1.8	1.5	
Do you think the death of this patient must be reported to the Federal Control and Evaluation Committee according to the euthanasia law? If you had performed this act, would you report?						<0.001
Must be reported, and I would report	10.9	9.1	18.1	68.4	11.0	
Must be reported, but I would not report	0.8	2.2	1.7	4.5	2.0	
Must not be reported	69.8	62.8	56.1	14.1	60.3	
Don't know	18.4	25.1	24.1	13.0	26.6	
Willingness to report the death of the patient according to physicians' labelling of the act						<0.001
Label 'euthanasia', would report	7.8	6.8	15.7	69.7	3.3	
Label 'euthanasia', would not report	2.9	2.7	4.5	11.6	2.7	
Label 'other than euthanasia', would report	8.0	8.9	9.5	4.8	13.3	
Label 'other than euthanasia', would not report	81.3	81.6	70.3	13.9	80.6	

See box 1 for exact descriptions of cases

Table 3 Factors associated with correct labelling of euthanasia cases *

	Euthanasia 1 (case 4)		Euthanasia 2 (case 3)	
	N (%)	**OR [95% CI]**	**N (%)**	**OR [95% CI]**
Region				
Wallonia	202 (70.4)	1	60 (21.5)	NS
Flanders	413 (89.0)	2.69 [1.52-4.75]	82 (18.2)	NS
Brussels	87 (74.4)	0.92 [0.53-1.58]	31 (27.4)	NS
I am sufficiently informed about the euthanasia law				
Yes	333 (86.0)	1.69 [1.11-2.57]	71 (19.0)	NS
No	366 (77.2)	1	100 (21.7)	NS
Attitude towards control over euthanasia†				
Pro	507 (84.4)	1.74 [1.16-2.62]	124 (21.5)	NS
Against	187 (73.9)	1	49 (19.9)	NS
Attitude towards euthanasia				
Pro	648 (82.1)	NS	147 (19.2)	1
Against	57 (70.4)	NS	26 (32.5)	1.87 [1.07-3.30]
Number of terminal patients cared for in the last 12 months				
0	152 (83.1)	NS	55 (30.6)	1
1-9	365 (80.8)	NS	77 (17.7)	0.49 [0.32-0.75]
≥10	127 (80.9)	NS	24 (15.6)	0.40 [0.22-0.71]

* Multivariate logistic regression. Presented figures are numbers and percentages correctly labelled, odds ratios and 95% confidence intervals. NS= not significant
Independent variables which have no significant relationships are not presented in the table. Sex, years experience as physician, training in palliative care, , religious affiliation, specialty, and whether a physician had ever performed euthanasia in practice were entered in the regressions but were not significant and were therefore eliminated from the table.
† K-means cluster analysis. Physicians are divided in two groups (pro or against control over euthanasia) according to their attitudes on three statements, assessed on a five-point Likert Scale. Statement 1: "Euthanasia is a private matter between patient and physician that does not need to be controlled by the Control and Evaluation Committee." Statement 2: "Societal control over the euthanasia practice is necessary." Statement 3: "Reporting euthanasia cases contributes to the carefulness of physicians' medical behavior at the end of life."

7.3.5 Factors associated with reporting of euthanasia cases

Physicians who labeled the euthanasia case in which the physician administers a sleep-inducing drug and a neuromuscular relaxant at the explicit request of the patient correctly were substantially more likely to know that this case had to be reported to the Review Committee than those who labeled it incorrectly (table 4). Controlling for labeling, other factors associated with higher likelihood of knowing that this case had to be reported were being female (OR 1.76), living in Flanders (OR 2.76), being sufficiently informed about the euthanasia law (OR 2.36), having a positive attitude towards euthanasia (OR 2.01), and having a positive attitude towards societal control over euthanasia (OR 2.53). Factors associated with willingness to report this euthanasia case were the same, except for attitude towards euthanasia, which had no influence.
Physicians who labeled the case in which the physician ended the patient's life at his/her request using morphine as 'euthanasia' were more likely to know that this case had to be reported than those who labeled this case differently. Controlling for labeling, other factors associated with higher likelihood of knowing that the case had to be reported were being religious without having a specific denomination (OR 5.72) and having a positive attitude towards societal control over euthanasia (OR 2.32). Factors associated with willingness to report this euthanasia case were the same. In addition, not having cared for terminal patients in the last year also increased a physician's willingness to report this case.

7.4 Discussion

Our study shows that there is a lack of agreement among physicians in Belgium about the classification of euthanasia and other end-of-life decisions, and about which cases must be reported as euthanasia to the Federal Review Committee. Seven years after implementation of the euthanasia law in Belgium, two out of ten physicians, likely to be involved in the care of dying patients, did not label a hypothetical case in which a physician ends the life of a patient at that patient's explicit request using neuromuscular relaxants (case 4) as 'euthanasia.' Three out of ten physicians did not know the case had to be reported to the Federal Review Committee. Most physicians labelled the euthanasia case in which the physician ends the life of a patient at that patient's explicit request using morphine (case 3) as 'intensification of pain and symptom treatment' (39%) or as 'palliative/terminal sedation'(37%); only 21% of physicians labelled this case as 'euthanasia'. Most physicians who knew the euthanasia case with neuromuscular relaxants (case 4) had to be reported indicated that they would report the case themselves. In particular the correct labelling of the euthanasia

case was strongly associated with whether a physician knew the case had to be reported and whether they would report the case themselves.

While we used a large representative sample of physicians and included only those specialties which are likely to be involved in the care of dying patients. A limitation of our study is that the response rate was only 34%, limiting the generalizability of the results. However, comparison of the responders and non-responders through our non-response survey suggests that the sample of responders was similar to the group that did not respond in terms of region, and in terms of whether or not they had ever received a request for euthanasia. Furthermore, we used hypothetical cases that are reductions of the complex situations that may occur in clinical reality.[11,25,26] However, all cases were tested with several specialists in the field of palliative care, who found the cases realistic and could answer the questions adequately. Furthermore, we cannot exclude the possibility of a social desirability bias, especially for the question of whether or not the physician would report the case. Finally, intended behavior and real behavior may not be identical as real behavior is known to be influenced by situational factors.[27-29]

Identical hypothetical cases were not uniformly labelled by physicians. Some cases were inaccurately labeled as 'euthanasia'. A consequence of this may be that these cases may also be unnecessarily reported to the Review Committee. Far more problematic is that this incorrect labelling of normal medical practice as euthanasia could prevent physicians from applying these adequate and often necessary end-of-life interventions. As shown in our study, a physician's willingness to perform end-of-life decisions such as palliative sedation or intensified pain alleviation was much lower if they labelled the case as 'euthanasia' or 'life-ending without explicit request.' This finding has implications that stretch well beyond the countries with a law on euthanasia; better knowledge about euthanasia and about the use and effects of opioids can contribute to better treatment of pain and other suffering.[30-32]
In light of the Belgian law on euthanasia, an important finding is that two out of ten physicians labelled the euthanasia case with neuromuscular relaxants (case 4) incorrectly and three out of ten were unaware of the legal reporting obligation.
The euthanasia case in which the physician ended the patient's life at his/her request using morphine (case 3) was labelled as euthanasia by only one in five of the physicians. When a patient requests that their life be ended and the physician in response disproportionally increases the morphine dose instead of administering neuromuscular relaxants the distinction between euthanasia and normal intensification of symptom treatment may become blurred. Cases in which the physician performs euthanasia with opioids are often not perceived as euthanasia by the physician.[10] Some physicians see a 'grey area' or continuum

Table 4 Factors associated with reporting of euthanasia cases*

	Euthanasia 1 (case 4)				Euthanasia 2 (case 3)			
	This case must be reported		I would report this case		This case must be reported		I would report this case	
	N (%)	OR [95% CI]	N (%)	OR [95% CI]	N (%)	OR [95% CI]	N (%)	OR [95% CI]
Sex								
Men	399 (70.9)	1	392 (71.0)	1	119 (21.2)	NS	134 (24.3)	NS
Women	240 (77.2)	1.76 [1.11-2.80]	232 (80.0)	2.07 [1.30-3.30]	56 (18.2)	NS	72 (26.3)	NS
Religious affiliation/ philosophy of life								
Roman Catholic	308 (74.4)	NS	302 (75.3)	NS	82 (19.8)	1.23 [0.64-2.35]	96 (24.6)	1.66 [0.84-3.31]
Other denomination	13 (61.9)	NS	13 (68.4)	NS	10 (50.0)	1.16 [0.54-2.50]	10 (52.6)	2.54 [1.14-5.66]
Religious, but no specific denomination	76 (75.2)	NS	69 (75.0)	NS	15 (15.2)	5.72 [1.59-20.51]	18 (19.6)	9.10 [2.36-35.14]
Humanist	104 (67.1)	NS	105 (69.5)	NS	34 (21.8)	0.96 [0.38-2.41]	47 (31.1)	1.63 [0.65-4.06]
Not religious	122 (79.7)	NS	118 (79.2)	NS	25 (16.4)	1	28 (19.3)	1
Region								
Wallonia	170 (59.9)	1	172 (62.1)	1	61 (21.2)	NS	72 (26.4)	NS
Flanders	397 (85.6)	2.76 [1.74-4.37]	381 (83.7)	1.73 [1.11-2.68]	89 (19.3)	NS	104 (23.5)	NS
Brussels	69 (57.0)	0.80 [0.45-1.42]	69 (64.5)	1.02 [0.60-1.90]	25 (21.4)	NS	30 (28.6)	NS
I am								

sufficiently informed about the euthanasia law								
Yes	320 (82.5)	2.36 [1.52-3.68]	316 (82.7)	2.14 [1.40-3.26]	80 (20.9)	NS	95 (25.8)	NS
No	313 (65.8)	1	302 (67.0)	1	88 (18.6)	NS	105 (23.6)	NS
Attitude towards euthanasia†								
Pro	590 (74.6)	2.01 [1.04-3.89]	576 (75.3)	NS	136 (22.8)	NS	162 (28.6)	NS
Against	48 (60.0)	1	47 (62.7)	NS	33 (13.3)	NS	36 (15.2)	NS
Attitude towards control over euthanasia‡								
Pro	480 (79.2)	2.53 [1.65-3.89]	477 (81.4)	3.32 [2.20-5.02]	136 (22.8)	2.32 [1.33-4.03]	162 (28.6)	2.39 [1.33-4.29]
Against	148 (59.0)	1	135 (56.5)	1	33 (13.2)	1	36 (15.2)	1
Labelling of the act								
Intensification of pain and symptom treatment	2 (4.9)	1	5 (12.2)	1	17 (5.3)	1	28 (8.9)	1
Euthanasia	604 (85.9)	92.57 [21.59-396.89]	584 (85.8)	43.15 [14.58-127.71]	120 (69.4)	45.92 [24.68-85.44]	126 (77.8)	44.07 [23.30-83.34]
Life-ending without request	11 (40.7)	7.84 [1.43-42.87]	12 (44.4)	5.18 [1.30-20.69]	4 (26.7)	3.09 [0.59-16.16]	5 (38.5)	4.40 [1.02-19.07]

Palliative/ Terminal Sedation	16 (20.0)	3.13 [0.65-15.09]	19 (25.3)	2.7 [0.82-8.96]	30 (9.6)	1.71 [0.89-3.29]	41 (13.7)	1.36 [0.76-2.44]
Other	6 (37.5)	16.31 [2.57-103.54]	4 (28.6)	4.09 [0.79-21.15]	1 (5.9)	1.24 [0.14-11.04]	3 (20.0)	1.93 [0.39-9.51]
Number of terminal patients cared for in the last year								
0	125 (70.2)	NS	131 (77.5)	NS	54 (29.7)	NS	69 (42.1)	1
1-9	337 (73.4)	NS	329 (73.6)	NS	76 (16.8)	NS	88 (20.2)	0.35 [0.20-0.61]
≥10	120 (76.9)	NS	109 (73.2)	NS	27 (17.3)	NS	26 (17.3)	0.26 [0.13-0.55]

* Multivariate logistic regression. Presented figures are numbers and percentages, odds ratios and 95% confidence intervals. NS= not significant
Independent variables which have no significant relationships are not presented in the table. Years of experience as physician, training in palliative care, specialty and whether a physician had ever performed euthanasia in practice were entered in the regressions but were not significant and were therefore eliminated from the table.

† Attitude towards euthanasia was measured on a five-point Likert scale using the statement: "The administration of life-ending drugs at the explicit request of a patient is acceptable for patients with a terminal disease with extreme, uncontrollable pain or other uncontrollable suffering." Physicians who answered that they 'agreed' or 'totally agreed' with the statement were classified as pro euthanasia; physicians who answered they 'disagreed', 'totally disagreed', or were neutral towards the statement were classified as being against euthanasia.

‡ K-means cluster analysis. Physicians are divided in two groups (pro or against control over euthanasia) according to their attitudes on three statements, assessed on a five-point Likert Scale. Statement 1: "Euthanasia is a private matter between patient and physician that does not need to be controlled by the Control and Evaluation Committee." Statement 2: "Societal control over the euthanasia practice is necessary." Statement 3: "Reporting euthanasia cases contributes to the carefulness of physicians' medical behavior at the end of life."

between palliation and euthanasia and find that the distinctions between the two are not always very clear-cut.[33]

A post-mortem survey on end-of-life decisions in Flanders found that most unreported euthanasia cases were not regarded as euthanasia by the physicians themselves.[10] Our findings also show that physicians who regarded the euthanasia cases as euthanasia were substantially more likely to know that these cases had to be reported and were substantially more willing to report the cases themselves than those who labelled the cases differently. Correct labelling is thus important to enable adequate societal control over the practice of euthanasia. The aforementioned study also found that euthanasia cases that were not labelled as euthanasia were dealt with less carefully than the cases that were.[10] If physicians have another definition of euthanasia than the definition determined by the euthanasia law then they will not be inclined to comply with the requirements of the law such as the mandatory consultation of a second independent physician. Correct labelling of euthanasia cases is thus also pivotal in guaranteeing the carefulness of the euthanasia practice.
A considerable number of physicians who labelled the cases correctly as 'euthanasia' did not know that they had to be reported, indicating a lack of knowledge of the law, a conclusion also suggested by the fact that not being sufficiently informed about the law was associated with lower awareness of the reporting obligations. Both correct labelling of end-of-life decisions and knowledge with regard to legal requirements thus seem important factors in explaining reporting behavior.

We found considerable regional differences in labelling and reporting knowledge and intentions with regard to the euthanasia case with neuromuscular relaxants (case 4): compared with physicians from Wallonia, Flemish physicians were 26 percentage points more aware of the legal requirement to report the case (86% vs 60%) and 22 percentage points more willing to report it (84% vs 62%). This is also reflected in the Review Committee's biennial reports: only about 15% of all reported euthanasia cases had been reported by French-speaking physicians. [34-37] The fact that Flemish physicians were more likely to label the euthanasia case correctly partly explains the difference in reporting. However, even after controlling for labelling, geographic region was still strongly associated with reporting knowledge and willingness. The geographic differences in labelling and reporting could be influenced by a difference in information dissemination.[34] Flanders shares the same language with the Netherlands, so Flemish physicians may have had better access to information from the Netherlands, which has seen a decades-long history of public debate about euthanasia, than have French-speaking physicians from Wallonia.[34] Furthermore, the establishment of the

LifeEndInformationForum (LEIF) in Flanders, a network of physicians trained to give expert advice and consultation on euthanasia and other end-of-life decisions, may also have played a role in informing Flemish physicians.[34;38-40]

Physicians were less likely to know that the euthanasia case with neuromuscular relaxants (case 4) had to be reported when they were against euthanasia and were less likely to label the euthanasia case correctly, to know that the case had to be reported and to be willing to report it themselves when they were against control over euthanasia. Those physicians who are against euthanasia or control over euthanasia may be less open to information about the euthanasia law and the legal reporting obligation than those with a more positive attitude, and will hence be less inclined to report their euthanasia cases in actual practice. If physicians who are unaware that euthanasia cases must be reported or who would not report a euthanasia case themselves were not willing to perform euthanasia in actual practice, our findings would be less problematic. However, a majority of these physicians could conceive of performing the euthanasia case themselves.

In conclusion, the reporting procedure for euthanasia is based on the premise that end-of-life decisions can be uniformly labeled and that physicians are able to classify those decisions according to the legally defined categories. Our hypothetical case study shows that identical cases are not uniformly labelled and that there is no complete agreement about which end-of-life decisions are considered to be euthanasia and which end-of-life decisions should not be labeled as euthanasia. Physicians sometimes label intensified pain alleviation or palliative/terminal sedation as euthanasia. Those physicians are less willing to perform these acts in practice. Incorrect labelling of normal medical practice as euthanasia could thus pose a barrier to effective pain treatment. Physicians who did not perceive the euthanasia cases in the study as euthanasia were less willing to report these cases themselves than those who did. This finding has profound repercussions for the working of the current system for societal control over euthanasia. Agreement about the labelling of end-of-life decisions is thus pivotal in countries where euthanasia is legal. Furthermore, our results show that there are large regional differences in labelling and reporting of euthanasia cases, which might be remedied by information campaigns specifically targeted at physicians from Wallonia. Further research should focus on investigating how exactly physicians come to label end-of-life decisions and which factors are decisive in their labeling.

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PART 3
ATTITUDES TOWARDS THE USE OF LIFE-ENDING DRUGS AND TOWARDS THE EUTHANASIA LAW

CHAPTER 8
ATTITUDES AND EXPERIENCES OF BELGIAN PHYSICIANS REGARDING EUTHANASIA PRACTICE AND THE EUTHANASIA LAW

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Abstract

Context
Since the legalization of euthanasia, physicians in Belgium may under certain conditions administer life-ending drugs at the explicit request of a patient.
Objectives
To study the attitudes of Belgian physicians towards the use of life-ending drugs and the euthanasia law, factors predicting attitudes, and factors predicting whether a physician has ever performed euthanasia.
Methods
In 2009, we sent a questionnaire to a representative sample of 3006 Belgian physicians who, due to their specialty, were likely to be involved in the care of the dying.
Results
Response rate was 34%. Ninety percent of physicians studied were acceptant towards euthanasia for terminal patients involving extreme uncontrollable pain/symptoms. Sixty six percent agreed that the euthanasia law contributes to the carefulness of physicians' end-of-life behavior; 10% agreed that the law impedes the development of palliative care. Religious beliefs and geographic region were strong determinants of attitude. Training in palliative care did not influence attitudes regarding euthanasia, but trained physicians were less likely to agree that the euthanasia law impedes the development of palliative care than were non-trained physicians. One in five physicians had performed euthanasia; they were more likely to be non-religious, older, specialist, trained in palliative care and to have had more experience in treating the dying.
Conclusion
A majority of the physicians studied support euthanasia for terminal patients involving extreme uncontrollable pain/symptoms and agree that euthanasia can be part of good end-of-life care. Although physicians had little involvement in the process of legalizing euthanasia, they now generally endorse the euthanasia law.

8.1 Introduction

In recent years significant developments in end-of-life care have taken place in Belgium. Apart from the promulgation of a law on palliative care in 2002, positing the right to palliative care for every patient and substantially increasing its funding,[1] the legalization of euthanasia [2] makes Belgium, along with the Netherlands and Luxembourg, one of the few countries in the world where euthanasia can be practiced legally in a medical context. Since 2002, physicians may under legally well-defined circumstances administer life-ending drugs at the explicit request of a patient. To make societal control over these far-reaching and controversial medical acts possible, the law includes a mandatory notification procedure requiring physicians to report each euthanasia case to the Federal Control and Evaluation Committee, which assesses whether or not the physician has respected all the requirements of the law.[2]

Since the enactment of the euthanasia law, the frequency and characteristics of end-of-life practices have been studied,[3] but the attitudes of physicians towards using life-ending drugs and towards the euthanasia law, and the factors associated with performing euthanasia, have not. The legalization of euthanasia in Belgium was the result of a short Parliamentary process and was finalized without the broad involvement of and consensus among the medical profession.[4,5] Investigating physicians' attitudes in a country with a euthanasia law is necessary to provide insight into how the law is perceived and supported by those directly involved and may contribute to the further understanding of the practice of euthanasia in Belgium. When a country considers legalizing euthanasia, insight into the attitudes of physicians towards the proposed rules and safeguards is important because their support of the law can be pivotal for it to be effective. By investigating the attitudes of physicians in a country with a euthanasia law, this study may contribute to the societal and ethical debate on euthanasia and may reveal information useful to other countries contemplating legislative changes on end-of-life practices.

This paper aims to answer the following research questions:

1) What are Belgian physicians' attitudes to the use of life-ending drugs and to the euthanasia law and which factors predict these attitudes?
2) What are Belgian physicians' experiences with euthanasia and which factors predict ever having performed euthanasia?

8.2 Methods

8.2.1 Study design

In 2009 we sent a questionnaire to 3,006 physicians in Belgium. The survey was self-administered and conducted by mail. The sample included only registered physicians who worked in Belgium, had finished formal postgraduate training at least one year before the sample was drawn and were likely to be more frequently involved in the care of the dying on the basis of their specialty. Physicians from the following 12 specialties were included: general practice, anesthesiology, gynecology, internal medicine, neurology, oncology, pulmonology, neuropsychiatry, psychiatry, cardiology, radiotherapy, and surgery. These chosen specialties excluded non-clinical specialties such as pathology, public health and microbiology, but we also excluded clinical specialties thought to have little or no experience of caring for the dying. The sample was stratified for province and specialty. For each province a random proportional sample was drawn for each specialty.

We sent an eight-page questionnaire to each physician in the sample. According to the Total Design Method an intensive follow-up mailing in case of non-response was performed with up to three reminders.[6] A rigorous procedure was implemented in the mailing procedure to guarantee that physicians remained anonymous. All questionnaires were given a sample number, which was linked to the sample database with the corresponding physician's name, address, province and specialty. The completed questionnaires were sent to a lawyer who safeguarded the anonymity of the physicians. We chose to work with a lawyer because we thought this would inspire confidence in the physicians as our survey included questions about illegal acts. Also, working with an intermediary is a more straightforward method to guarantee anonymity than for example providing respondents with a separate post card that they would have to return separately from the survey. The lawyer removed the sample numbers and any other identifying information from the questionnaires. These cases were subsequently marked in the sample database so that these physicians did not receive further reminders. As removing the sample numbers from the questionnaires would make it impossible to link them to the corresponding physician's province and specialty at the end of the study, which was necessary for weighting procedures, the lawyer ascribed a new number to every questionnaire and kept a database in which the original sample numbers and the corresponding new numbers were linked to one another. At the end of the survey, the lawyer deleted the original sample numbers and the physicians' names and addresses so that identifying physician information could no longer be linked to the information in the questionnaires. The lawyer transmitted the questionnaires and the new database to the researchers.

We performed a non-response survey, asking non-responding physicians for their reasons for not participating in the study. In order to estimate non-response bias, we also assessed their answers on two key variables: their attitude towards euthanasia using the same question as in the original questionnaire (see statement 1 in table 3) and whether they had ever received a request for euthanasia.
Positive recommendations for the anonymity procedure and study protocol were obtained from the Ethical Review Board of the University Hospital of the Vrije Universiteit Brussel.

8.2.2 Measurement instrument

The pre-structured questionnaire drew partly on questionnaires previously used in the Netherlands, in several European countries and in Australia.[7,8] Questions were adapted to make them appropriate for the Belgian legal context and culture. The questionnaire was developed in Flemish, and forward-backward translated into French for use in the French-speaking part of Belgium. The questionnaire was tested with ten physicians who were experts in palliative care using cognitive testing. The physicians suggested improved and unambiguous question wording, layout and routing. These suggestions were all incorporated in the final questionnaire.
In addition to questions on socio-demographic and work-related characteristics, questions were asked about attitudes and practices concerning euthanasia. This paper focuses on attitudes towards using life-ending drugs and towards the euthanasia law, assessed through a list of 10 statements (as shown in table 3). All statements were tested with several physicians. Value-laden terms such as 'euthanasia' were avoided as much as possible. We instead described the act as 'the administration of life-ending drugs at the explicit request of a patient.' Only when referring to the euthanasia law did we use the term euthanasia but the legal definition of euthanasia was first given above the statements ("Euthanasia is the intentional life-ending act by a physician at the explicit request of the patient").
Agreement with each statement was measured on a five-point Likert scale (strongly agree, agree, neutral, disagree, strongly disagree). We asked whether or not the physician had ever performed euthanasia.
Physician characteristics considered in this paper are sex, age (<35, 36-50, 51-65, >65), religious affiliation/philosophy of life based on a question about religious denomination and one on religious services attendance (Roman Catholic: strongly practicing, Roman Catholic: moderately practicing, Roman Catholic: not practicing, Protestant, humanist, other religion/philosophy of life, religious but no specific religion, not religious), region (Flanders, the Flemish speaking part of Belgium, Wallonia, the French-speaking part, and Brussels),

specialty (general practitioner, specialist), years of experience as a physician (<10, 11-20, 21-30, 31-40, >40), training in palliative care (no/ yes, in basic training for physicians/yes, continuing education or postgraduate course/ yes, other training), part of palliative team/service (yes/no), number of terminal patients cared for in the last 12 months (0, 1-9, ≥10).

8.2.3 Statistical analysis

When presenting frequencies and fitting regression models a weighting factor was used to correct for stratification, making the data representative for all physicians in the sample. Data were weighted by comparing the response population with the total sample on the variables 'specialism' and 'region'. Differences between response population and total sample were tested bivariately using crosstabs. Significant differences were found only for region. The percentages of physicians in each region in the total sample were divided by percentages of physicians in each region in the response population. A weighting coefficient was subsequently calculated. Weighted percentage of agreement (agree or strongly agree), disagreement (disagree or strongly disagree) and neutral position with statements and 95% confidence intervals are reported. A separate multivariate ordinal logistic regression (PoLitomous Universal Models; i.e. PLUM) has been fitted for each statement to estimate the association with physician socio-demographic and work-related characteristics, experiences with end-of-life care and euthanasia, and religious affiliation. To obtain good final models and to get a clear view of how factors influence attitudes, variables were entered into the model stepwise. Non-significant variables were eliminated from the models. Significance level was set at 0.05. When the parallel lines assumption in multivariate ordinal logistic regression, that is the regression lines are parallel for each level of the dependent, was violated, categories of the dependent ordinal variables were combined until parallelism was achieved.
Multivariate logistical regression was performed to estimate predictors of ever having performed euthanasia. Odds ratios and 95% confidence intervals are presented. The analyses were performed using SPSS 16.0 (SPSS Inc., Chicago, IL) and StatXact 6.

8.3 Results

8.3.1 Response rate and non-response bias

3,006 questionnaires were sent to physicians from specialties likely to be involved in the care of dying patients. Physicians from the following specialties

were not contacted: dermatology, pediatrics, nuclear medicine, ophthalmology, orthopedics, plastic surgery, rheumatology, stomatology, radiology, physical therapy and otorhinolaryngology. The not contacted specialties comprise a fraction of 20% of the physicians in Belgium.
Of the 3,006 questionnaires sent, response was impossible for 223 respondents. Of the remaining 2783 questionnaires, 914 were returned. To assess non-response bias, non-responders were sent a one-page questionnaire, asking them for the reasons for nonparticipation; 583 replied. The response rate to the non-response survey was 31%. Table 1 compares the responders to the survey with the responders to the non-response survey and with the non-responders to both the survey and the non-response survey. Table 2 shows the answers to the non-response survey. Not being involved in the care of dying patients, never responding to questionnaires and having no time to respond to questionnaires were the main reasons for non-response. Those who no longer worked as a physician (N=32) or who did not receive the questionnaire (N= 25) were subtracted from the denominator of our study sample. The response rate of the study was thus 34%.

Table 1 Comparison of responders to the survey with responders to the non-response survey and all non-responders

Physician characteristic	Responders survey N=914 (%)	Responders non-response survey N= 583 (%)	Complete non-response N=1509 (%)
Specialty			
General practice	561 (61.8)	422 (72.4)	980 (64.9)
Medical specialist	347 (38.2)	161 (27.6)	529 (35.1)
Region			
Flanders	480 (52.8)	300 (51.5)	756 (50.1)
Wallonia	305 (33.6)	201 (34.5)	548 (36.3)
Brussels	123 (13.6)	82 (14.0)	205 (13.6)
Ever received euthanasia request (yes)	429 (47.8)	223 (46.0)	NA
Attitude towards euthanasia			NA
Agree/strongly agree	822 (90.4)	425 (87.4)	
Neutral	37 (4.1)	43 (8.8)	
Disagree/strongly disagree	49 (5.5)	18 (3.7)	

NA denotes not available
Significant differences between responders survey and responders non-response survey were found for specialty ($p<0.001$) and attitude towards euthanasia ($p=0.001$); significant differences between responders non-response survey and all non-responders to both the survey and non-response survey were found for specialty ($p=0.001$); no significant differences were found between responders survey and all non-responders to both the survey and non-response survey

In order to assess non-response bias, non-responders were also asked to give their attitude towards euthanasia (statement 1 in table 3) and whether or not they had ever received a request for euthanasia. Although both groups strongly agreed that the administration of life-ending drugs at the explicit request of a patient is acceptable for patients with a terminal disease involving extreme, uncontrollable pain or other uncontrollable suffering, non-responders were somewhat less likely to agree (84.7% versus 90.4%, p=0.001) and were more neutral toward the statement than responders (8.8% versus 4.0%, p=0.001). No significant difference between responders and non-responders was found for the question whether or not the physician had ever received a request for euthanasia (48.3% of responders versus 46.0% of non-responders had ever received a request for euthanasia; p=0.405).

Table 2 Reasons indicated for not responding by physicians not participating to the study

Reasons	N=583	% Agreeing
I am not involved in the care of dying patients	191	33.2
I never respond to questionnaires	172	29.7
I don't have time to respond to questionnaires	156	26.9
The questionnaire was too long	107	18.5
I did not trust the assurances of anonymity	36	6.2
I no longer work as a physician	32	5.5
I did not receive the questionnaire	25	4.3
The wording of the questionnaire was biased	23	4.0
I only reply to questionnaires if offered a fee	22	3.6
I don't agree with doing research on euthanasia	16	2.8

8.3.2 Characteristics of responding physicians

Table 3 shows the characteristics of the respondents. Sixty four percent of responding physicians were men, 62% were general practitioners, 61% had more than twenty years of experience as a physician and 48% had received training in palliative care.

Table 3 Characteristics of the study population

	N=914	%
Sex		
Men	576	63.5
Women	323	35.6
Age		
<35	110	12.4
36-50	323	36.7
51-65	398	45.1
>65	51	5.8
Religious affiliation/philosophy of life		
Roman-Catholic: strongly practicing	144	16.5
Roman-Catholic: moderately practicing	196	22.5
Roman-Catholic: not practicing	88	10.1
Humanist	163	18.7
Other religion/philosophy of life	21	2.4
Religious, but no specific denomination	104	12.0
Not religious	155	17.8
Region		
Flanders	480	52.8
Wallonia	305	33.6
Brussels	123	13.6
Specialty		
General practice	561	61.8
Anesthesiology	75	8.2
Internal medicine	73	8.0
Psychiatry	41	4.6
Surgery	30	3.3
Gynecology	28	3.1
Cardiology	28	3.1
Neuropsychiatry	12	1.3
Neurology	11	1.2
Pulmonology	11	1.2
Radiotherapy	4	0.5
Years experience as physician		
<10	148	16.6
11-20	202	22.6
21-30	287	32.1
31-40	216	24.1
>40	40	4.5
Training in palliative care		
Yes [a]	433	48.1
In basic training for physicians	133	30.4
Continuing education or postgraduate course	375	85.8
Other training	46	10.5
Part of palliative team/service		
Yes	47	5.3
Number of terminal patients cared for in the last 12 months		
0	202	24.5
1-5	406	49.2
6-10	111	13.5
11-20	64	7.7

>20	42	5.1
Ever performed euthanasia (yes)	179	19.7

All percentages and total numbers are adjusted for stratification
[a] More than 1 answer possible

8.3.3 The attitudes of Belgian physicians regarding the use of life-ending drugs

Ninety percent of physicians accepted euthanasia for patients with a terminal disease involving extreme, uncontrollable pain or other uncontrollable suffering (table 4). Seventy five percent agreed that euthanasia can be considered part of good end-of-life care. Sixty percent agreed that the physician should be able to decide to administer life-ending drugs if a patient suffers unbearably but is not capable of making decisions on their own. Half of physicians (52%) are more prepared to perform continuous deep sedation than euthanasia.
Nineteen percent would in no circumstances be prepared to perform euthanasia themselves.

8.3.4 The attitudes of Belgian physicians regarding the euthanasia law

Sixty eight percent of physicians agreed that societal control over euthanasia practice is necessary. The euthanasia law prescribes a number of requirements for a careful euthanasia practice which physicians are legally required to comply with and which could contribute to improving medical decision-making at the end of life. Sixty-six percent agreed that the euthanasia law contributes to the carefulness of a physician's medical practice at the end of life. Sixty four percent agreed that reporting euthanasia cases contributes to the carefulness of a physician's medical practice at the end of life. Twenty seven percent agreed that euthanasia is a private matter between patient and physician that does not need to be controlled by the Control and Evaluation Committee and ten percent agreed that the euthanasia law impedes the further development of palliative care.

8.3.5 Determinants of physicians' attitudes regarding the use of life-ending drugs

Practicing Roman Catholic physicians were less accepting of euthanasia and were more likely to be willing to perform continuous deep sedation instead of euthanasia compared with non-religious physicians. They were also less likely to agree that a physician should be able to administer life-ending drugs if a patient suffers unbearably but is not capable of making decisions on their own, and

that euthanasia can be part of good end-of-life care (table 5). Physicians from Wallonia more often agreed that they would in no circumstances perform euthanasia themselves, and were more willing to perform continuous deep sedation instead of euthanasia than were those from Flanders and from Brussels. Walloon physicians were also less likely to support the statement that euthanasia can form part of good end-of-life care. Physicians from Brussels were more likely to accept life-ending without the patient's request than were those from Flanders and Wallonia. Older physicians more often agreed that they would in no circumstances perform euthanasia themselves and that they would rather perform continuous deep sedation instead of euthanasia compared with younger physicians. They also agreed less often that euthanasia can form part of good end-of-life care. Physicians without training in palliative care and those who had cared for ten or more terminal patients in the last 12 months were more likely to support life-ending without the patient's request than were those with training in palliative care and those who had cared for fewer terminal patients.

8.3.6 Determinants of physicians' attitudes regarding the euthanasia law

Compared with non-religious physicians, practicing Roman-Catholics were less likely to agree that the euthanasia law contributes to the carefulness of end-of-life behavior. However, they were also more likely to agree that societal control over euthanasia is necessary, and that reporting of euthanasia contributes to the carefulness of end-of-life behavior (table 6). Physicians from Wallonia and Brussels were more likely than Flemish physicians to believe that euthanasia is a private matter between patient and physician. Older physicians, general practitioners, those without training in palliative care, and practicing Roman Catholics were more likely to support the statement that the euthanasia law impedes the development of palliative care than were younger physicians, specialists, those with training in palliative care and non-religious physicians. Physicians without training in palliative care were also more likely to agree that euthanasia is a private matter between patient and physician that does not need to be controlled by the Control and Evaluation Committee, and were less likely to agree that societal control over euthanasia is necessary and that reporting of euthanasia contributes to the carefulness of end-of-life behavior than were those with training in palliative care.

Table 4 Attitudes of physicians towards using life-ending drugs and the euthanasia law (n=914)

		Disagree or strongly disagree		Neutral		Agree or strongly agree	
		%	(95% CI)	%	(95% CI)	%	(95% CI)
Statements on using life-ending drugs							
1	The administration of life-ending drugs at the explicit request of a patient is acceptable for patients with a terminal disease with extreme, uncontrollable pain or other uncontrollable suffering	5.5	(3.8 – 7.4)	4.1	(2.7 – 5.9)	90.4	(88.0 – 92.7)
2	Life-ending at request of a patient can be part of good end-of-life care	12.9	(10.3 – 15.9)	11.9	(9.4 – 14.7)	75.2	(71.6 – 78.6)
3	If a terminally ill patient suffers unbearably and is not capable of making decisions on their own, the physician (together with the team of caregivers) should be able to decide to administer life-ending drugs	20.6	(17.4 – 24.0)	19.6	(17.0 – 23.0)	59.8	(55.9 – 63.8)
4	I am more prepared to perform continuous deep sedation at request of a patient than to administer life-ending drugs at request of a patient	23.8	(20.4 – 27.3)	24.5	(21.2 – 28.1)	51.6	(47.7 – 55.7)
5	I am in no circumstances prepared to administer drugs to hasten death at the explicit request of a patient	62.8	(58.9 – 66.7)	18.7	(15.7 – 22.0)	18.6	(15.6 – 21.9)
Statements on the euthanasia law							
1	Societal control over the euthanasia practice is necessary	13.2	(10.7 – 16.0)	19.3	(16.3 – 22.6)	67.5	(63.7 – 71.3)
2	The euthanasia law contributes to the carefulness	12.7	(10.2 – 15.5)	21.5	(18.3 – 24.9)	65.8	(62.0 – 69.6)

	of physicians' medical behavior at the end of life						
3	Reporting euthanasia cases contributes to the carefulness of physicians' medical behavior at the end of life	13.7	(11.1 – 16.7)	22.5	(19.3 – 26.0)	63.8	(59.9 – 67.7)
4	Euthanasia is a private matter between patient and physician that does not need to be controlled by the Control and Evaluation Committee	54.5	(50.0 – 58.6)	18.2	(15.2 – 21.4)	27.3	(23.8 – 31.0)
5	The euthanasia law impedes the further development of palliative care	71.5	(67.9 – 75.1)	18.4	(15.4 – 21.6)	10.1	(7.8 – 12.7)

All percentages are adjusted for stratification

Table 5 Factors predicting physicians' support for the statements on using life-ending drugs, multivariate ordinal regression[a] (n=914)

Predictor	Statement 1: Acceptance of euthanasia		Statement 2: Euthanasia as part of good end-of-life care		Statement 3: Life-ending without request in incompetent patients [e]		Statement 4: Willingness to perform sedation instead of euthanasia [e]		Statement 5: Refusal to perform euthanasia [e]	
	OR	**95% CI**	**OR**	**95% CI**	**OR**	**95% CI**	**OR**	**95% CI**	**OR**	**95% CI**
Religious aff./ philosophy of life										
Roman-Catholic: strongly practicing	**0.17**	**0.10-0.29**	**0.25**	**0.16-0.39**	**0.37**	**0.23-0.60**	**2.76**	**1.67-4.59**	**2.92**	**1.77-4.84**
Roman-Catholic: Moderately pract.	**0.43**	**0.26-0.72**	**0.49**	**0.32-0.74**	0.85	0.54-1.34	**1.64**	**1.05-2.55**	**1.85**	**1.14-3.00**
Roman-Catholic: not practicing	0.59	0.32-1.11	0.63	0.38-1.05	0.98	0.55-1.75	1.40	0.80-2.44	1.66	0.92-2.97
Humanist	1.60	0.85-3.02	1.23	0.79-1.92	1.41	0.85-2.35	0.85	0.54-1.34	0.75	0.43-1.30
Other religion	**0.10**	**0.04-0.24**	**0.19**	**0.08-0.44**	**0.22**	**0.09-0.57**	1.44	0.56-3.68	**3.07**	**1.26-7.48**
Religious, no denomination	0.61	0.34-1.10	**0.53**	**0.33-0.86**	0.76	0.45-1.28	1.14	0.69-1.89	**1.75**	**1.01-3.03**
Not religious	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
Region										
Flanders	[b]	[b]	1.00	1.00-1.00	1.00	1.00-1.00	1.00	1.00-1.00	1.00	1.00-1.00
Wallonia	[b]	[b]	**0.42**	**0.32-0.56**	1.24	0.91-1.70	**1.60**	**1.16-2.19**	**1.70**	**1.24-2.33**
Brussels	[b]	[b]	0.72	0.48-1.06	**1.78**	**1.10-2.87**	1.35	0.88-2.06	1.21	0.77-1.90
Age [c]										
<35	[b]	[b]	1.00	1.00-1.00	[b]	[b]	1.00	1.00-1.00	1.00	1.00-1.00
36-50	[b]	[b]	0.69	0.45-1.04	[b]	[b]	**1.59**	**1.03-2.46**	1.40	0.87-2.26
51-65	[b]	[b]	0.75	0.50-1.14	[b]	[b]	**2.30**	**1.49-3.57**	**1.80**	**1.12-2.89**

>65	[b]	[b]	**0.43**	**0.22-0.82**	[b]	[b]	**5.82**	**2.43-13.97**	**3.00**	**1.47-6.15**
Training in palliative care[d]										
Yes	[b]	[b]	[b]	[b]	1.00	1.00-1.00	[b]	[b]	[b]	[b]
No	[b]	[b]	[b]	[b]	**1.44**	**1.06-1.95**	[b]	[b]	[b]	[b]
Number of terminal patients cared for in last yr										
0	[b]	[b]	[b]	[b]	1.00	1.00-1.00	1.00	1.00-1.00	[b]	[b]
1-9	[b]	[b]	[b]	[b]	0.90	0.62-1.29	**2.03**	**1.44-2.86**	[b]	[b]
≥10	[b]	[b]	[b]	[b]	**1.62**	**1.02-2.60**	**2.49**	**1.60-3.88**	[b]	[b]
Ever performed euthanasia										
Yes	1.00	1.00-1.00	1.00	1.00-1.00	[b]	[b]	1.00	1.00-1.00	1.00	1.00-1.00
No	**0.31**	**0.19-0.51**	**0.40**	**0.28-0.57**	[b]	[b]	**2.85**	**1.96-4.13**	**7.17**	**4.06-12.67**
Model fitting information										
Pseudo R square [f]	0.18		0.18		0.10		0.15		0.18	

[a] Separate ordinal regression models were performed for each statement. The full description of the statements is presented in table 3.
Presented figures are odds ratios and 95% confidence intervals. Independent variables which have no significant relationships are not presented in the table.
Sex and specialty were entered in the regressions but were not significant for any of the statements and were therefore eliminated from the table.
[b] Entered in the regression but not significant and consequently eliminated from the model.
[c] A problem of multi-collinearity between age and years of experience as physician made us omit the latter.
[d] A problem of multi-collinearity between being part of a palliative team/service and training in palliative care made us omit the first.
[e] The parallel lines assumption in multivariate ordinal logistic regression was violated, that is the regression lines were not parallel for each level of the dependent. Categories of the dependent ordinal variables were therefore combined until parallelism was achieved. "Disagree" and "strongly disagree" were combined into one category, "neutral" is a category, and "agree" and "strongly agree" were combined into one category.
[f] Nagelkerke

Table 6 Factors predicting physicians' support for the statements on the euthanasia law, multivariate ordinal regression[a] (n=914)

Predictor	Statement 1 Societal control over euthanasia is necessary		Statement 2: Euthanasia law contributes to carefulness end-of-life behavior		Statement 3: Reporting contributes to carefulness end-of-life behavior		Statement 4: Euthanasia is private matter between patient and physician [c]		Statement 5: Euthanasia law impedes development of palliative care	
	OR	**95% CI**	**OR**	**95% CI**	**OR**	**95% CI**	**OR**	**95% CI**	**OR**	**95% CI**
Sex										
Men	b	b	b	b	b	b	b	b	1.48	1.10-1.98
Women	b	b	b	b	b	b	b	b	1.00	1.00-1.00
Religious aff./ philosophy of life										
Roman-Catholic: strongly practicing	**1.70**	**1.12-2.58**	**0.27**	**0.17-0.41**	**1.70**	**1.12-2.58**	0.68	0.43-1.08	**4.07**	**2.59-6.39**
Roman-Catholic: Moderately pract.	1.04	0.71-1.53	**0.58**	**0.40-0.87**	1.04	0.71-1.53	0.71	0.46-1.07	**2.14**	**1.41-3.26**
Roman-Catholic: not practicing	1.42	0.88-2.30	0.73	0.45-1.17	1.42	0.88-2.30	1.10	0.66-1.84	1.47	0.87-2.47
Humanist	0.83	0.56-1.24	1.03	0.68-1.56	0.83	0.56-1.24	1.06	0.69-1.63	1.03	0.66-1.61
Other religion	2.30	0.94-5.64	**0.26**	**0.11-0.58**	2.30	0.94-5.64	**0.17**	**0.05-0.65**	**4.06**	**1.68-9.85**
Religious, no denomination	1.35	0.86-2.14	**0.62**	**0.39-0.98**	1.35	0.86-2.14	**0.54**	**0.32-0.89**	**1.80**	**1.10-2.93**
Not religious	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
Region										
Flanders	b	b	b	b	b	b	1.00	1.00-1.00	b	b
Wallonia	b	b	b	b	b	b	**2.13**	**1.58-2.87**	b	b
Brussels	b	b	b	b	b	b	**1.67**	**1.12-2.49**	b	b
Age [c]										

<35	b	b	b	b	b	b	b	b	1.00	1.00-1.00
36-50	b	b	b	b	b	b	b	b	1.06	0.69-1.61
51-65	b	b	b	b	b	b	b	b	1.03	0.67-1.59
>65	b	b	b	b	b	b	b	b	**2.35**	**1.19-4.64**
Specialty										
GP	b	b	b	b	b	b	b	b	**1.36**	**1.03-1.80**
Specialist	b	b	b	b	b	b	b	b	1.00	1.00-1.00
Training in palliative care [d]										
Yes	1.00	1.00-1.00	b	b	1.00	1.00-1.00	1.00	1.00-1.00	1.00	1.00-1.00
No	**0.66**	**0.52-0.85**	b	b	**0.66**	**0.52-0.85**	**1.60**	**1.22-2.10**	**1.33**	**1.01-1.74**
Ever performed euthanasia										
Yes	b	b	1.00	1.00-1.00	b	b	b	b	1.00	1.00-1.00
No	b	b	**0.56**	**0.40-0.77**	b	b	b	b	**1.49**	**1.05-2.12**
Model fitting information	0.04		0.09		0.04		0.08		0.11	
Pseudo R square [f]										

[a] Separate ordinal regression models were performed for each statement. The full description of the statements is presented in table 3.
Presented figures are odds ratios and 95% confidence intervals. Independent variables which have no significant relationships are not presented in the table. Years of experience as physician and number of terminal patients care for in the last 12 months were entered in the regressions but were not significant for any of the statements and were therefore eliminated from the table.
b Entered in the regression but not significant and consequently eliminated from the model.
[c] A problem of multi-collinearity between age and years of experience as physician made us omit the latter.
[d] A problem of multi-collinearity between being part of a palliative team/service and training in palliative care made us omit the first.
[e] The parallel lines assumption in multivariate ordinal logistic regression was violated, that is the regression lines were not parallel for each level of the dependent. Categories of the dependent ordinal variables were therefore combined until parallelism was achieved. "Disagree" and "strongly disagree" were combined into one category, "neutral" is a category, and "agree" and "strongly agree" were combined into one category.
[f] Nagelkerke

Table 7 Predictors of performing euthanasia [a] (n=914)

	OR	95% CI
Religious affiliation/philosophy of life		
Roman-Catholic: strong practicing	**0.30**	**0.15-0.60**
Roman-Catholic: moderately practicing	**0.49**	**0.27-0.89**
Roman-Catholic: not practicing	**0.41**	**0.18-0.91**
Humanist	1.05	0.60-1.84
Other religion/ philosophy of life	0.00	0.00-0.00
Religious, but no specific denomination	**0.33**	**0.16-0.70**
Not religious	1.00	1.00-1.00
Specialty		
General practitioner	1.00	1.00-1.00
Specialist	**1.98**	**1.29-3.03**
Age [b]		
<35	1.00	1.00-1.00
36-50	**2.25**	**0.99-5.14**
51-65	**3.43**	**1.53-7.67**
>65	**4.15**	**1.37-12.56**
Training in palliative care [c]		
Yes	**1.85**	**1.21-2.83**
No	1.00	1.00-1.00
Number of terminal patients cared for in the last 12 months		
0	1.00	1.00-1.00
1-9	**3.60**	**1.84-7.04**
≥10	**6.58**	**3.23-13.43**
Model fitting information		
Pseudo R square [d]	0.20	

[a] Multivariate logistic regression. Presented figures are odds ratios and 95% confidence intervals. Independent variables which have no significant relationships are not presented in the table. Sex and region were entered in the regression but not significant and consequently eliminated from the model.

[b] A problem of multi-collinearity between age and years of experience as physician made us omit the latter because age was found to be a stronger predictor than years of experience as physician.

[c] A problem of multi-collinearity between being part of a palliative team/service and training in palliative care made us omit the first.

[d] Nagelkerke

8.3.7 Predictors of performing euthanasia

One in five (19.7%) physicians had at some time performed euthanasia (table 7). Non-religious physicians were more likely to have performed euthanasia than Roman Catholics and religious physicians with no specific denomination. Other factors associated with a higher likelihood of having performed euthanasia included being a specialist, being of an older age, having had training in palliative care and having cared for terminal patients in the last 12 months.

8.4 Discussion

Our study shows that there is broad support among Belgian physicians for euthanasia for patients with a terminal disease involving extreme, uncontrollable pain or other suffering. Physicians generally agree that the existing euthanasia law contributes to the carefulness of a physician's behavior at the end of life and few believe the euthanasia law impedes the further development of palliative care. The need for societal control over the practice of euthanasia is generally endorsed by Belgian physicians. However, one in three agrees that euthanasia is a private matter between patient and physician that does not need to be controlled by the Control and Evaluation Committee. Religious beliefs and geographic region are strong determinants of the attitudes of physicians towards euthanasia and the euthanasia law. Training in palliative care does not influence a physician's attitude regarding euthanasia, but those trained in palliative care are less likely to believe that the euthanasia law

impedes the further development of palliative care and are more likely to agree with the need for societal control over the euthanasia practice than are non-trained physicians. One in five physicians had performed euthanasia themselves. They were more likely to be non-religious, older, specialist, trained in palliative care and to have had more professional experience in treating the terminally ill.

This is the first study since the legalization of euthanasia in Belgium that assesses the attitudes of physicians to the use of life-ending drugs and the euthanasia law. We used a large sample of physicians from specialties which are likely to be involved in the care of dying patients. Physicians from specialties not likely to be involved in the care of the dying were excluded because the topics of the study are not relevant to those physicians' medical practice.

Our results show that physicians' attitudes are in line with findings from previous empirical studies on end-of-life practices in Belgium.[9-13]

The questionnaire was comprehensively tested. The study was endorsed by the Ethical Review Board of the University Hospital of the Vrije Universiteit Brussel.
Our study also has limitations. The survey response rate was only 34%, limiting the generalizability of the results. The response rate of our non-response survey was also only 31%. Comparison of the responders and non-responders through our non-response survey, however, did suggests that the sample of responders was quite similar to the group that did not respond in terms of region, and in terms of whether or not they had ever received a request for euthanasia. However, non-responders were slightly, but significantly less supportive of euthanasia than responders, indicating some response bias. The 50.2% of the sampling frame who did not respond to either the survey or the non-response survey are likely to be different to the sample as non-responders might have less experience with terminally ill patients and have a more ambiguous attitude towards end-of-life decisions [14] Furthermore, we cannot exclude that the physicians in the different regions may have given different answers due to the different languages they were answering in.
We used a commercial register because recent privacy laws made official registers with personal physician information from the National Institute for Health and Disability Insurance (NIHDI) unavailable to researchers. Only aggregated data are provided by the NIHDI. The commercial database contained information that is based on information from the NIHDI. As all physicians in Belgium are compelled to register themselves with the NIHDI, both registers should correspond. The difference is that inactive physicians are more likely to be in the NIHDI database and less likely to be on the commercial database as the commercial agency contacts the physicians regularly to check whether the data are still up to date. We compared the commercial database with data from the NIHDI for province and specialty and there were no significant differences between the two databases on these variables.

Nine out of ten Belgian physicians agree with euthanasia for terminal patients with extreme uncontrollable pain or other uncontrollable suffering. This seems to be a very high acceptance rate, especially considering the limited support for euthanasia legislation among physicians in other countries.[15-17] Belgian physicians may be more accepting of euthanasia because the practice is now legal and there have been no apparent cases of abuse. Comparison with a survey conducted in 2002 in Belgium shows that the acceptance of euthanasia among physicians in Belgium has increased from 78% in 2002 to 90% in 2009.[8] The ongoing public debate about euthanasia in the media since legalization may have made it less of a taboo and may have led to an increasing awareness of the rights of terminally ill patients and to an increase in the acceptance of euthanasia in general.[18]

A striking finding is that, although still a criminal offense under Belgian law, more than half of Belgian physicians endorse the use of life-ending drugs in patients who suffer unbearably and are not capable of making decisions on their own. The acceptance of this practice is very high in Belgium, and was the highest in a study of seven countries conducted in 2002 where the same question was asked.[8] This may be linked to differences in emphasis on patient autonomy in different countries. In situations of unbearable and irreversible suffering Belgian physicians may be more prepared than physicians in other countries to take decisions on behalf of their patients.[19,20] Interestingly, physicians with more experience in caring for the terminally ill were more likely to agree with this end-of-life practice, which seems to suggest that more personal and direct confrontation with the pain and suffering of patients leads to the view that life-ending in incompetent patients is a justifiable option where suffering cannot otherwise be alleviated. This idea is supported by a similar study with nurses that found that bedside nurses were more accepting of life-ending in incompetent patients than nurses who were not involved in direct patient care.[9] Physicians trained in palliative care, however, were less likely to agree with life-ending without patient request than were non-trained physicians. This is possibly linked to the strong focus in palliative care on patient autonomy at the end of life.[21]

Contrary to the beliefs of many experts in the field of palliative care, Belgian physicians generally agree that life-ending at the request of the patient can be part of good end-of-life care and only a few agree that the euthanasia law impedes the further development of palliative care.[22-24] Having received training in palliative care did not influence the attitude of Belgian physicians towards euthanasia. Moreover, physicians who were trained in palliative care were actually less likely to perceive the euthanasia law as having a negative effect on the development of palliative care and were more likely to have performed euthanasia than were non-trained physicians. This is a striking finding because studies conducted in other countries on physicians' attitudes towards the legalization of euthanasia often find that those trained in palliative care are strong opponents of euthanasia legislation, arguing that physicians agree with euthanasia because they feel incompetent in treating the dying and that better training in palliative care may change their views.[15,17,25] Our study results do not support this view, but are actually in line with what has been found in previous empirical studies conducted in Belgium.[2,12] One study found that palliative care and euthanasia are often not seen as mutually exclusive alternatives by Belgian caregivers, but rather as integral aspects of end-of-life care.[2] Data from another study indicate that euthanasia often occurs in the context of multidisciplinary palliative care.[12] The strong opposition between euthanasia and palliative care thus seems not to exist in the minds of Belgian physicians with expertise in palliative care.

Our study shows important differences in the attitudes of physicians according to geographic region. Flemish physicians were more willing to perform euthanasia themselves than those from the French-speaking Walloon region, and Walloon physicians more often agreed that they would rather perform continuous deep sedation than euthanasia compared with their colleagues from Flanders. Walloon physicians were also less likely to agree that euthanasia can be part of good end-of-life care. Physicians from Brussels for their part had a significantly higher acceptance of the use of life-ending drugs without the patient's request. These differences in attitudes are reflected in actual medical end-of-life practices between the regions in Belgium found in other empirical studies.[5,11] A nationwide mortality follow-back study via a sentinel network of general practitioners found a tendency towards more euthanasia in Flanders and more continuous deep sedation in Wallonia.[11] Another study found that the incidence of the use of life-ending drugs without the patient's request was significantly higher in Brussels than in Flanders.[5] The fact that our results on attitudes are supported by data on end-of-life practices seems to suggest that there is an association between attitudes and practices. The difference in attitudes towards end-of-life decisions may be due to possible cultural differences between the Germanic north, the Roman south, and metropolitan Brussels. Also, the establishment of the LifeEndInformationForum (LEIF) project in Flanders may have played a role in informing Flemish physicians who care for dying patients about euthanasia and the euthanasia law. LEIF is a network of physicians who are trained to give expert advice and consultation on euthanasia and other end-of-life decisions.[26,27] A similar network does not exist in Wallonia. We hypothesize that being informed about euthanasia and about the prerequisites of the euthanasia law could influence physicians' support for the practice. However, further research is needed to explore the regional differences in attitudes

The need for societal control over the practice of euthanasia is generally endorsed by Belgian physicians. However, one in three agrees that euthanasia is a private matter between patient and physician that does not need to be regulated by the Control and Evaluation Committee; physicians from Wallonia especially believe that euthanasia should not be controlled by a Committee. This is an interesting finding when considering that only about 15% of the euthanasia cases reported to the Federal Control and Evaluation Committee had been reported by French-speaking physicians.[28-30] It is often assumed that this very large difference does not reflect a very large difference in actual practice, but rather a reluctance to report euthanasia cases.[28-30] Although Walloon physicians are less likely to agree to performing euthanasia, their more negative views about societal control over euthanasia by a Committee and the fact that geographic region was not predictive of whether a physician had ever performed euthanasia suggest that the lower reporting rate in Wallonia is at

least partly due to a lower level of willingness to report euthanasia cases. We hypothesize that this could be an expression of a stronger inclination to paternalism in Walloon physicians compared with their Flemish colleagues. Again, it is also possible that the establishment of LEIF in Flanders since the enactment of the euthanasia law has played a role in educating Flemish physicians. Further research should focus on exploring ways in which societal control may become acceptable to all physicians.

We conclude that seven years after legalization, there is a substantial majority of Belgian physicians supporting the practice of euthanasia for the terminally ill experiencing extreme uncontrollable pain or other uncontrollable symptoms, and most think euthanasia has a place in good end-of-life care. Our study shows that Belgian physicians trained in palliative care and those with more experience with caring for the dying are more likely to be involved in euthanasia performance than non-trained physicians and physicians with less experience in caring for the dying. Furthermore, the holding of religious views is strongly related to unwillingness to perform euthanasia and to willingness to perform sedation instead of euthanasia. Physicians in Belgium generally support the euthanasia law despite their lack of involvement in the process leading up to the enactment of the law.

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PART 4
MAIN FINDINGS AND GENERAL DISCUSSION

CHAPTER 9
MAIN FINDINGS AND GENERAL DISCUSSION

9.1 Introduction

This dissertation provides insight into the medical practice of euthanasia in Belgium with a specific focus on physicians' adherence to legal safeguards and their reporting of euthanasia cases. In this chapter, an overview of the strengths and limitations of the employed study designs will be given. Then the most important results of the studies will be described, followed by an interpretation and discussion of the findings. The chapter will conclude with a number of implications and recommendations for policy and practice and with suggestions for future research.

9.2 Methodological considerations, strengths and limitations

In this dissertation, four different studies were used: a study of the official databases of all reported cases of euthanasia from the Belgian Federal Control and Evaluation Committee and the Dutch Regional Euthanasia Review Committees, a death certificate study, the SENTI-MELC study, and a nationwide physician survey. All studies have strengths as well as some limitations that will be discussed in this paragraph.

9.2.1 Study of official databases of reported cases of euthanasia from the Belgian Federal Control and Evaluation Committee and the Dutch Regional Euthanasia Review Committees

We obtained the databases of all officially reported cases of euthanasia in Belgium between implementation of the euthanasia law on September 22, 2002 and the end of 2007. The databases contained 1,917 reported cases of euthanasia and consisted of the information collected from the official euthanasia registration forms sent in by the reporting physicians. We analyzed the information in the databases to gather insight into the reported practice of euthanasia in Belgium. By studying as many as 1,917 cases, our study offers valuable information on the reported practice of euthanasia. The databases were obtained from the Committee itself, which systematically contacted physicians when important information was missing from the registration form.[1-3]

There are also limitations in the study based on these databases. The methods of our study rely on the analysis of data collected as part of the reporting procedure and based on the registration forms. Therefore, certain information that would have provided a more complete insight into the studied cases eg on palliative interventions were not included and those aspects could not be

studied. Furthermore, not all the variables from the registration form were included in the database and some variables were not registered for each year, complicating the interpretation of the results. Also, because of the anonymous nature of the reporting procedure and the confidentiality of the data, we could not contact the reporting physicians for more information. Finally, a possible social desirability bias also has to be taken into account as physicians may have presented their cases in compliance with the law on euthanasia so as to minimize the risk of criminal prosecution.

To compare the characteristics of all reported cases of euthanasia in Belgium with the reported cases in the Netherlands, we also obtained the databases of the reported cases of euthanasia from the Dutch Review Committees. These databases contained information about 10,319 reported cases between September 2002 and December 2007, thus offering valuable insight into the reported practice of euthanasia in the Netherlands. Limitations of this study are the same as for the study based on the databases from the Belgian Federal Review Committee. An additional limitation for the comparative study was that, due to the use of different registration forms, the variables in the databases from both countries were not always identical, complicating analysis of the data and interpretation of the results.

9.2.2 Death certificate study

The death certificate study has a quantitative, retrospective design. A stratified random sample was drawn from death certificates of those aged one year or older in Flanders, Belgium. The certifying physician of each included death was sent a questionnaire on end-of-life decision-making in the death concerned.[4] Major strengths of the death certificate study are that the method has been proved to be very reliable for estimating incidences of end-of-life decisions in a population.[5-10] As the sample is composed of an at random sample of death certificates, all deaths have a theoretically equal probability to be included in the sample. Also, analyses of death certificate data are not limited to specific patient populations and settings. Furthermore, questionnaires can be linked to data from the death certificates, providing information about patient characteristics, and allowing the researchers to correct the response sample for these patient characteristics. Finally, full anonymity was guaranteed via a complex mailing procedure involving a lawyer.

The death certificate study also has some limitations. Physicians report on deaths that occurred sometime before filling in the questionnaire, creating a possible recall bias. However, measures were taken to minimise recall bias: questionnaires were sent to the physicians as soon as possible after the death of

the patient, and physicians were encouraged to consult the patient's medical file when filling in the questionnaire. Furthermore, the study is based on physicians' self-reporting. The retrospective design implies that physicians have to reconstruct end-of-life decision making retrospectively. Therefore, errors in the perception of their acts, eg. life-shortening effect of the drugs they administered, cannot be excluded. It is also possible that they did not remember all aspects of a case well and we cannot exclude a social desirability bias, especially for the question of whether or not the physician had reported the case to the Federal Review Committee. Further, the quantitative design of the study makes it more difficult to gather insight into the complexities of medical-decision making and the psychological mechanism underlying physicians' reporting behavior. Also, as recent death certificate data are not available for Wallonia, the French-speaking southern part of Belgium, the design cannot be used to gain insight into end-of-life decision making in Wallonia. The reporting rate could therefore also not be estimated for the whole country. Finally, although the response rate of the study was 58%, which is satisfactory for this sort of survey considering the increasing demands made on doctors to participate in research activities, [11,12] some non-response bias is possible.[13]

9.2.3 The SENTI-MELC study, a retrospective study via the Belgian Sentinel Network of General Practitioners

The SENTI-MELC study has a quantitative, retrospective design. General practitioners registered deaths weekly and immediately after they learned of them, using a standardized form.[14] A large interview study was subsequently conducted with GPs who had reported a death of a patient who was at least one year old at the time of death, and had died non-suddenly at home or in a care home. In this dissertation we studied data of nine interviews conducted with GPs who had reported a death that was the result of euthanasia. Strengths of the study are that the cases were selected from the large-scale two-year retrospective mortality study representative of all non-sudden deaths in Belgium and are therefore likely to be representative of euthanasia cases at home in the country. Furthermore, the reliability of the surveillance system from which GPs were selected for interview has been demonstrated.[15-17] Another strength is that the collected data are considered to be of high quality because the cooperation of the GPs in the network is optimal, because all interviews were conducted face to face by two researchers and as soon as possible after inclusion, and because quality control measures were used in both the registration and the interview study, such as data-entry with consistency, range and skip checks. Finally, recall bias was minimized as interviews were conducted within a few months of the GP registering the case.

The study also has some limitations. During the two-year study period, only 11 cases of euthanasia were identified and an interview could be conducted in only nine of these. The study conclusions are thus based on a very small number of cases and the results have to be interpreted cautiously. Furthermore, the study is limited to euthanasia cases at home and cannot claim to be representative of euthanasia practice in hospitals or care homes. Also, due to the retrospective design of the study a possible recall bias could not be excluded entirely, or some decisions might have been interpreted differently a posteriori. Lastly, as interviews were conducted with GPs about their own adherence and non-adherence to the due care requirements of the euthanasia law, the possibility of a social desirability bias cannot be excluded.

9.2.4 Nationwide physician survey

For the nationwide physician survey we used a large representative sample of physicians and included only those specialties that are likely to be involved in the care of dying patients. The questionnaire was based on those used in previous research [83] and was comprehensively tested with several specialists in the field of palliative care, other physicians and one of the chairs of the Federal Review Committee. All questions could be answered adequately. The hypothetical cases included in the questionnaire were found to be realistic descriptions of clinical situations. The questionnaire was forward-backward translated by a professional translation agency to minimize the risk that differences in the results between Flemish and French speaking physicians might be caused by the different languages they responded in.

The physician survey also has limitations. A major limitation is that the response rate was only 34%, limiting the generalizability of the results. The length of the questionnaire, which was eight pages, may have posed a barrier for many physicians to participation in the study. The delicate and controversial nature of the topic of euthanasia may also have prevented several physicians from participating. Although a non-response analysis revealed that most physicians who had not responded indicated that they did not participate because they did not have time to respond to questionnaires or because they were not involved in the care of dying patients, it cannot be precluded that physicians who were most interested in the research topic of euthanasia are overrepresented in the sample of physicians. Comparison of responders and non-responders through our non-response survey suggested that non-responders had a somewhat less positive attitude towards euthanasia than responders. However, results from our non-response survey also suggested that the sample of responders was quite similar to the group that did not respond regarding region and whether or not they had ever received a request for

euthanasia. Furthermore, the use of a quantitative research design to study attitudes makes it more difficult to study the complexities of and the nuances in physicians' attitudes.

Several limitations in our study about the labelling and reporting of cases of euthanasia are linked to our use of hypothetical cases of clinical situations. Hypothetical cases are clearly reductions of the complex situations that may occur in clinical reality.[18-20] Furthermore, we cannot exclude the possibility of a social desirability bias, especially for the question of whether or not the physician would report the hypothetical case themselves if had performed it. Finally, intended behavior and real behavior may not be identical as real behavior is known to be influenced by situational factors.[21-23]

9.3 Main Findings

In the introduction of this dissertation several research questions were formulated. In this section, the main findings to each of those research questions are presented concisely.

9.3.1 What do the reporting, control and evaluation procedures for euthanasia entail in Belgium and in the Netherlands? What are the similarities and differences in the procedures between both countries? What are the possible implications of the differences in the procedures for a safe and controllable euthanasia practice?

The reporting, control and evaluation procedures for euthanasia in Belgium and the Netherlands

Based on a study of all the relevant official documents relating to the reporting, control and evaluation procedures for euthanasia in Belgium and the Netherlands such as euthanasia laws and reports from the Review Committees, the similarities and differences between the procedures in both countries were described and discussed in Chapter 2. Belgium and the Netherlands have both developed procedures for reporting and controlling euthanasia in medical practice. The main purpose of these procedures is to guarantee good practice, to stimulate physicians to report their cases for review and to make societal control over the practice of euthanasia possible. Although the procedures are quite similar in Belgium and the Netherlands, there are also some marked differences.

In both countries physicians are legally required to report each case of euthanasia performed to a Review Committee using a standardized registration

form. In Belgium, physicians are to send the form directly to the Federal Control and Evaluation Committee; in the Netherlands, they must notify the medical examiner and send the registration form, together with several additional forms such as the report from the second physician consulted to the medical examiner. The medical examiner then sends a report on his findings, together with the documents from the physician, to one of five Regional Euthanasia Review Committees.

With regard to the registration forms, we found that the Dutch form was more elaborate and contained more open-ended questions than the Belgian form. The Belgian form is anonymous, whereas the Dutch is not.

In Belgium, there is one central Federal Review Committee, while there are five Regional Review Committees in the Netherlands. In both countries, the Committees function as a buffer between the physicians and the judicial authorities. The Committees in both countries control whether or not the physician has complied with all the requirements and procedures of the euthanasia law. If a physician did not act carefully in accordance with the law, the Review Committee can ask the physician for additional information on the case and if necessary report the case to the judicial authorities for further investigation, in Belgium to the King's Prosecutor, in the Netherlands to the Assembly of Prosecutors-General and the Regional Inspector for health care. Euthanasia cases are in principal dealt with anonymously in Belgium. As the reporting procedure is not anonymous in the Netherlands, the Dutch Review Committees can contact the reporting physician directly, making open dialogue possible. Reporting physicians in the Netherlands also systematically receive feedback from the Review Committees about their actions. In Belgium, systematic open dialogue and feedback are not possible due to the anonymous nature of the reporting procedure.

In both countries societal evaluation of euthanasia practice is made possible through the Review Committee reports. The Committee reports contain information about the reported cases of euthanasia to inform the general public and to evaluate the implementation of the law. The Committees can also propose amendments to the law if necessary. In Belgium, the Federal Review Committee reports biennially to the Federal Parliament; in the Netherlands the Review Committees report jointly and annually to the Minister of Health, Welfare and Sport, and to the Minister of Justice, who in turn report to Parliament.

Implications for a safe and controllable euthanasia practice

The differences in the reporting, control and evaluation procedures in Belgium and the Netherlands may have important practical implications.
The fact that there is only one, central, Review Committee in Belgium that controls all reported cases of euthanasia could provide a better guarantee of uniformity in the control of the medical practice of euthanasia than does the Dutch system with five regional Review Committees. Furthermore, Dutch physicians are required to add several documents to the registration form, providing the Review Committees with more information than the Belgian Committee which judges solely on the registration forms. Extensive reporting dossiers might contribute to better-grounded decisions.
The Dutch procedures are more elaborate than the Belgian and require more effort from the physicians to fulfill. The procedures could be experienced as burdensome, possibly making physicians more hesitant to report their cases. A reporting procedure that requires a lot of effort to fulfill could also influence physicians in choosing alternative options without as many procedural requirements such as continuous deep sedation.
Although the Belgian reporting procedure was made anonymous at the request of the physicians and could therefore increase their willingness to report, the systematic feedback from the Dutch Review Committees improves the transparency of the Dutch reporting procedure. Through direct dialogue and discussion with the reporting physicians, the Review Committees can contribute to the improvement of medical-professional decision-making in euthanasia practice. The feedback and the Committee reports can have an important educational value and can therefore promote the quality and the meticulousness of euthanasia practice.

9.3.2 What are the characteristics of the reported cases of euthanasia in Belgium? Has there been a change in the characteristics over the years? What are the similarities and the differences in the characteristics of the reported cases of euthanasia in Belgium and in the Netherlands?

The characteristics of the reported cases of euthanasia in Belgium and changes in characteristics

Based on an analysis of the databases of all the cases of euthanasia reported by physicians between 22 September 2002 and 31 December 2007, described in Chapter 3, we found that the total number of reported cases in Belgium was 1,917. The number of reported cases increased each year from 235 cases in 2003, 347 in 2004, 388 in 2005, 428 in 2006, to 495 in 2007. The majority of

cases (83.1%) were reported by Dutch-speaking physicians with only a minority reported by French-speaking physicians (16.9%).

Of all reported cases, 52.7% of the subjects were men and 47.3% were women. Most patients who received euthanasia were between 40 and 79 years old (82.1%). Euthanasia occurred rarely in patients of 80 years or older: 17.9% of all reported cases were in elderly patients and their proportion among the reported cases of euthanasia did not increase significantly over the years. Euthanasia occurred in hospital in slightly more than half of all cases (51.7%) and in 42.2% of all cases at home. Euthanasia occurred rarely in a care home (4.3%). There was no significant change in place of death throughout the years. In comparison with all deaths in Flanders and Brussels (data from Wallonia not available), younger patients were clearly overrepresented among the cases of euthanasia (82% vs. 50%), while patients of 80 years or older were underrepresented (18% vs. 50%). Patients who received euthanasia died more often at home than was the case for all deaths in the population (42% vs. 22%). Most patients who received euthanasia suffered from cancer (82.5%), while a minority suffered from other diseases such as neuromuscular disease (8.3%) or cardiovascular disease (2.4%). In the population of all deaths the proportions were reversed: about one in four deaths (23.5%) was the result of cancer, while the majority of deceased persons (76.5%) had another cause of death.

Physicians reported unbearable physical suffering in almost all reported cases of euthanasia (95.6%). Psychological suffering was reported in fewer but still a substantial number (68.0%). When physical suffering was reported, it concerned most often pain (53.6%) or cachexia/exhaustion (32.5%). Reported psychological suffering most often consisted of loss of dignity/despair (42.5%). Most patients were considered to be terminally ill (93.4%). Non-terminally ill patients made up 6.6% of the reported cases and their proportion among the reported cases did not increase significantly over the years. Whereas terminally ill patients suffered mostly from cancer (87.6%), non-terminally ill patients suffered mostly from diseases other than cancer, such as progressive or non-progressive neuromuscular disease (51.6%) or cardiovascular disease (8.9%). Psychological suffering was reported significantly more often for non-terminal patients (89.7% vs. 66.5%), whereas the reverse was true for physical suffering (96.0% vs. 89.7%).

Almost all cases of euthanasia were based on the oral request of a competent patient (97.9%); only 2.1% of all cases were based on a written advance euthanasia directive from a patient in a coma or persistent vegetative state.
The second, legally required, independent physician consulted was most often a specialist (44.7%) or a general practitioner (42.9%). Over the years however, general practitioners were more often consulted as second independent

physicians. The consulted third independent physician required in non-terminally ill patients was in most cases a psychiatrist (60.3%). In one third of all cases the physician had consulted more physicians than legally required; however the number of additionally consulted physicians decreased every year. In one third of cases the physician had consulted a palliative team and the number of consulted palliative teams did not change over the years.
The drugs used to perform euthanasia were almost always barbiturates and/or neuromuscular relaxants. Morphine was used in only 0.9% of reported cases.

Comparison with the Netherlands

In Chapter 4 reported cases of euthanasia and physician-assisted suicide in Belgium and the Netherlands were compared. Compared with Belgium, there were many more cases of euthanasia and physician-assisted suicide reported in the Netherlands (N=10319). Gender and age distributions of reported cases were the same in both countries. However, we found that while most subjects suffered from cancer in both countries, they more often suffered from diseases of the nervous system in Belgium than in the Netherlands (8.3% vs. 3.9%). Another difference between the two countries was that euthanasia occurred more often at home in the Netherlands (81% vs. 42%), while it occurred more often in hospital in Belgium (52% vs. 9%). In the Netherlands, all cases were based on the oral request of a competent patient; in Belgium 2.1% of the cases were based on the written advance euthanasia directives of patients in a coma or a persistent vegetative state.

9.3.3 What is the rate of reporting euthanasia cases to the Federal Control and Evaluation Committee? What reasons do physicians have for not reporting cases of euthanasia, and what are the factors that are associated with reporting and non-reporting?

The reporting rate for euthanasia in Flanders

Based on the data from the death certificate study we estimated that 52.8% of all cases of euthanasia performed in Flanders in 2007 were reported to the Federal Review Committee (see Chapter 6).

Reasons for non-reporting

The reason most often mentioned by physicians in the death certificate study (Chapter 6) for not reporting a case of euthanasia was that the physician did not

consider the case to be one of euthanasia (in 77% of the non-reported cases). Other reasons mentioned for non-reporting were that reporting is too much of an administrative burden (18%), that the legal due care requirements had possibly not all been met (12%), that euthanasia is a private matter between physician and patient and because of possible legal consequences (2%).
In the interview study with nine GPs from the Sentinel Network of General Practitioners described in Chapter 5, the same reasons for non-reporting were mentioned. Another reason mentioned for non-reporting in that study was that the physician had forgotten to report.

Factors associated with reporting and non-reporting

Our studies indicated that the factor that was most strongly associated with non-reporting of euthanasia was the labelling of the end-of-life decision by the physician involved. In the study described in Chapter 6 we found that the reporting rate for euthanasia increased to 93.1% if it was calculated based only on those cases that were also labelled as 'euthanasia' by the physicians themselves. The reporting rate for cases labelled other than euthanasia was much lower: 7.8%. Significant relationships between reporting of euthanasia and the patient's age and the time by which life was shortened found in bivariate analyses did not hold after controlling for labelling of the end-of-life decision.

Whether a physician knew a euthanasia case had to be reported and whether they were willing to report the case themselves was also found to be strongly related to how the physician labelled the case in our study of hypothetical cases described in Chapter 7. Physicians who labelled euthanasia cases correctly as 'euthanasia' were substantially more likely to know that the cases had to be reported and to be willing to report them themselves than those who labelled euthanasia cases incorrectly. Factors associated with a higher likelihood of labelling a euthanasia case correctly were living in Flanders, being sufficiently informed about euthanasia law and having a positive attitude towards societal control over euthanasia practice.

How a physician labels a case of euthanasia is also likely to be related to the drugs used to perform it. In our study of hypothetical cases, 80.9% of the physicians labelled a case in which the physician used neuromuscular relaxants and barbiturates as 'euthanasia', while only 20.5% of the physicians labelled one performed with morphine as 'euthanasia'. In the study of reported and unreported cases of euthanasia described in Chapter 6, we found that the reporting rate of cases of euthanasia performed with barbiturates and/or

neuromuscular relaxants was much higher than the reporting rate of cases performed with other drugs such as morphine (92.9% vs. 4.8%).

Controlling for labelling, other factors were also found to be associated with a higher likelihood of knowing that euthanasia cases had to be reported and willingness to report them themselves in our study of hypothetical cases. Those factors were being female, living in Flanders, being sufficiently informed about the law, having a positive attitude towards euthanasia, and having a positive attitude towards societal control over euthanasia practice. Factors associated with willingness to report a case of euthanasia were the same, except for attitude towards euthanasia, which did not influence it.

9.3.4 To which degree do physicians in Belgium adhere to the legal due care criteria for euthanasia in medical practice? What are their reasons for non-adherence?

In Chapter 5, we studied the degree to which general practitioners in Belgium adhered to the legal safeguards in nine cases of euthanasia and their reasons for non-adherence. Most of those interviewed were aware of the legal safeguards and tried to adhere to them in their practice. Substantial legal requirements concerning the patient's request for euthanasia and their medical situation were met in all nine cases. All patients had made a voluntary and well-considered request for euthanasia and all patients were in a condition for which medical treatment was unavailing and there were no prospects of improvement. However, the procedural consultation and reporting requirements were in some of the cases ignored. In three cases the physician did not consult a second physician. Reasons mentioned for not consulting a second independent physician were that the physician did not think this consultation was necessary as they did not consider it a clear case of euthanasia (n=2); because the legal consultation procedure was too burdensome and not useful and because it was, according to the physician, up to the patient and physician alone to make the decision (n=1). In four of the nine cases studied the physician did not report the case to the Federal Review Committee. Cases of euthanasia were less often reported when the physician did not consider them to be euthanasia, when opioids were used to perform the euthanasia and when there had been no consultation of a second legally required independent physician.

In our study of reported and unreported cases of euthanasia described in Chapter 5 we found that the legal safeguards were less often adhered to in the unreported cases of euthanasia than in the reported cases.

9.3.5 Are there differences between reported and unreported cases of euthanasia with regard to characteristics of due care?

In Chapter 6, reported and unreported cases of euthanasia were compared with regard to characteristics of due care. A verbal and written request for euthanasia were present in 73.1% of all reported cases; in 87.7% of the unreported cases only a verbal request was present and the legally required written request was lacking. The involvement of other persons in the decision-making, especially other physicians and specialists in palliative care, took place significantly more often in reported cases of euthanasia than in unreported cases. Discussion of the decision with the nursing staff, relatives or other persons occurred equally often in unreported cases as in reported cases. Whereas95.6% of reported cases were performed with barbiturates and/or neuromuscular relaxants, which are the recommended drugs for euthanasia, the majority of the unreported cases (90.5%) were performed with non-recommended drugs, mainly opioids. The drugs were in all reported cases administered by a physician, as legally required. However, in 41.3% of the unreported cases the drugs were administered by a nurse. In these cases opioids or sedatives were always involved. Unreported cases of euthanasia were thus generally dealt with less carefully than reported cases.

9.3.6 What are Belgian physicians' attitudes towards the use of life-ending drugs and towards the euthanasia law? Which factors are associated with these attitudes?

Acceptance of euthanasia was generally high among physicians in Belgium who are likely to be involved in the care of the dying: 90.4% agreed that the practice is acceptable for patients with a terminal disease with extreme, uncontrollable pain or other uncontrollable suffering. Acceptance, however, was lower among practicing Roman Catholic physicians. The willingness to perform euthanasia was also high (62.8%), but lower than the acceptance of euthanasia in general. Practicing Roman Catholic physicians, physicians from Wallonia, and physicians older than 50 were more likely to refuse to perform euthanasia themselves than were non-religious physicians, physicians from Flanders, and those younger than 50 years.
Slightly more than half of the physicians would rather perform continuous deep sedation at the request of a patient than to administer life-ending drugs at request of a patient. This group contained especially practicing Roman-Catholics, physicians from Wallonia, those older than 35, and those who had cared for terminal patients in the last year.
More than half of the physicians (59.8%) accepted the practice of life-ending without request in incompetent patients. Acceptance was highest among non-

religious physicians, physicians from Brussels, physicians without training in palliative care and those who had cared for more than ten terminal patients in the last year.

The majority of the physicians (75.2%) agreed that euthanasia can be part of good end-of-life care and only a few (10.1%) agreed that euthanasia law impedes the further development of palliative care. Again, practicing Roman Catholic physicians, those from Wallonia and older physicians were less likely to think that euthanasia has a part in good end-of-life care. Practicing Roman Catholic physicians, older physicians, general practitioners and physicians without training in palliative care were more likely to agree that euthanasia law impedes the further development of palliative care than non-religious physicians, younger physicians, specialists, and physicians with training in palliative care.
The statement that the euthanasia law contributes to the carefulness of a physician's end-of-life behavior was also supported by 65.8% of the studied physicians. Again, the holding of religious views was associated with lower support.
With regard to attitudes towards the reporting of euthanasia cases we found that most physicians agreed that societal control over the practice of euthanasia is necessary (67.5%) and that reporting of euthanasia cases contributes to the carefulness of physicians' medical behavior at the end of life (63.8%). However, one in four physicians is also of the opinion that euthanasia is a private matter that does not need to be controlled by the Federal Review Committee. Physicians from Wallonia and Brussels and physicians who had not followed training in palliative care were more likely to agree that euthanasia is a private matter than were physicians from Flanders and those with training in palliative care.

9.3.7 Which factors predict whether or not a physician has ever performed euthanasia?

One in five physicians who are likely to be involved in the care of dying patients had at some time performed euthanasia. Factors associated with a higher likelihood of having performed euthanasia included being non-religious, being a specialist, being of an older age, having had training in palliative care and having cared for terminal patients in the last 12 months.

9.4 General discussion

In 2002, Belgium adopted a euthanasia law regulating intentional life-ending by a physician at the explicit request of a patient. Ethical, legal and societal control over the practice of euthanasia were deemed prerequisites for effective legislation. Indeed, the debate about the legalization of euthanasia often centers around questions concerning the possibility of effective control over the practice of euthanasia once it is legalized. How to make sure the practice is adequately controllable and how to guarantee the carefulness of the practice are important and challenging issues to be faced. As described in part 1 of this dissertation, the legalization of euthanasia in Belgium implied the establishment of due care requirements, embedded in law to safeguard the carefulness of euthanasia practice, and the creation of a reporting procedure. The reporting procedure aims to stimulate physicians to report their cases for review, to safeguard the quality of their euthanasia practice, and to make societal control over the practice of euthanasia possible.
The studies described in this dissertation aim to describe and evaluate euthanasia practice and the reporting procedure in Belgium, and provide findings on which future policy decisions could be grounded.

9.4.1 Frequency of reported cases of euthanasia and reporting rate

The first question to be answered, if one wants to evaluate the current reporting procedure, is how many of the cases of euthanasia that are being performed in practice are actually being reported by physicians. The death certificate study has provided data on the estimated total number of euthanasia cases performed in Flanders in 2007. By combining this number with the number of cases that physicians reported in that same year, an overall reporting rate for euthanasia could be estimated. In 2007, the reporting rate for euthanasia in Flanders was estimated at 52.8%. This means that half of all cases of euthanasia that were performed were being reported and controlled by the Federal Review Committee and half were not. How to interpret this finding is quite difficult as this is the first time since euthanasia was legalized that a reporting rate has been estimated. Data on the estimated total number of euthanasia cases are not available for the years since legalization of euthanasia prior to 2007, so it is difficult to tell whether the reporting rate has actually increased compared to prior years or not. What is known is that the total number of cases of euthanasia officially reported to the Federal Review Committee has more than tripled from 235 in 2003 to 822 in 2009.[1-3] Although the incidence of euthanasia in Flanders, as estimated through large-scale death certificate studies, has also increased from 1.1% in 1998 [9] to 1.9% in 2007 [24], the spectacular and consistent yearly increase in the number of reported

euthanasia cases leads one to suspect that the reporting rate for euthanasia has also increased since legalization.

Besides the rise in the incidence of euthanasia, there are several other factors that may explain the strong yearly increase in the total number of reported cases of euthanasia. First, it is likely that physicians have become more aware of the legal reporting requirement as euthanasia has been very much debated since its legalization and has become a more established practice. Second, because of the many debates about euthanasia in the public sphere, euthanasia has become a more accepted, albeit obviously it is still exceptional practice.[25] Our research has shown that the acceptance of euthanasia among physicians in Belgium indeed increased after its legalization. Physicians no longer have to act secretly and may therefore have become more inclined to bring their life-ending acts into the open. And finally, the risk of criminal prosecution that reporting could involve has proved to be minimal. The Federal Review Committee has never sent a case of euthanasia to the judicial authorities for further investigation[1-3] which has probably provided a sense of security for physicians and may have made them more confident in reporting their cases.[26] Our research supports this hypothesis as in only a few of the unreported cases of euthanasia in the death certificate study the physician mentioned fear of criminal prosecution as a reason for not reporting.

Comparison with the Netherlands

Despite the consistent increase in the number of reported cases of euthanasia, half of all cases of euthanasia are still not being reported. Compared to the Netherlands where a similar reporting procedure exists and where the reporting rate was estimated at 80.2% in 2005 [10], the reporting rate in Flanders is still low. Our study of reported and unreported cases of euthanasia based on death certificate data has suggested one possible explanation for this. That study has shown that there are more unclear cases of euthanasia in Flanders than in the Netherlands, cases in which opioids and/or sedatives are used instead of neuromuscular relaxants and in which the estimated term of life-shortening is small. These less clear-cut euthanasia cases are often not perceived as euthanasia by the physicians and are consequently not being reported. In the Netherlands, the number of such less clear-cut cases of euthanasia is much smaller.[10]

Another possible explanation for the lower reporting rate in Flanders is that Dutch physicians are more used to being open about their life-ending practices. Euthanasia had been a tolerated practice for decades before the practice was officially legalized in 2002 and physicians have since the early 1980s been stimulated by the Royal Dutch Medical Association to bring their life-ending

acts into the open, long before an official reporting procedure was first developed in the early 1990s.[27-29] Compared with Dutch physicians, being open about medical acts and allowing end-of-life practices to be controlled by an external Committee is therefore a relatively new experience for Belgian physicians. Moreover, it has taken many years in the Netherlands to reach the current reporting rate; it was estimated at only 18.0% in 1990 and then slowly increased to 40.6% in 1995, 54.1% in 2001 to reach the level of 80.2% in 2005[30]. It is likely that the reporting rate for euthanasia will similarly increase further in Flanders.

Flanders versus Wallonia

There is a lacuna in the research on reporting of euthanasia in Wallonia, the southern French-speaking part of the country. Death certificate data are not available for that part of the country so we could not unfortunately estimate a reporting rate for Belgium as a whole. However, our study in Chapter 3 has shown that only about 15% of all cases of euthanasia reported to the Federal Review Committee were reported by French-speaking physicians and 85% by Dutch-speaking physicians.[1-3] Although one study found a tendency towards a higher prevalence of euthanasia in Flanders than in Wallonia, the difference was not statistically significant and was not large enough to explain the disproportionate percentages observed in the reported cases of euthanasia.[1-3,31,32] French-speaking physicians therefore seem to report their cases less often to the Federal Review Committee than Dutch-speaking physicians. One possible explanation is that French-speaking physicians are less well-informed about euthanasia law and the reporting requirements as the media coverage on euthanasia is lower and training initiatives for physicians are less frequent than in the Dutch-speaking community.[33]
Our study on hypothetical cases described in Chapter 7 indeed indicated that Walloon physicians were less likely to know that the case in which the physician performs euthanasia with neuromuscular relaxants had to be reported than were Flemish physicians. Additionally, our nationwide survey among physicians has shown that attitudes towards societal control over the practice of euthanasia differ between the two communities: Walloon physicians are less in favour of societal control over euthanasia practice than are Flemish physicians and may therefore be less willing to report their cases. We can thus conclude that the disproportionate percentages observed in the reported cases of euthanasia in Flanders and Wallonia are likely not only to be linked to possible differences in end-of-life practices, but also to differences in knowledge and attitudes among physicians in the two communities.

9.4.2 Reporting or not reporting

Knowing that half of all cases of euthanasia are not being reported, it is important to understand the reasons physicians have for not reporting cases of euthanasia and the factors related to reporting and non-reporting. By gaining insight into those reasons and factors we can see where and how transparency can be further improved.

Labelling as principal associated factor

The death certificate study for the first time provided information on reasons for non-reporting and factors related to reporting and non-reporting. For all unreported cases of euthanasia the physicians were asked about the reasons for non-reporting. The reason mentioned in three out of four of the unreported cases was that the physician did not perceive their act as euthanasia. The same main reason for non-reporting was also found in the Netherlands.[10,34] The fact that how a physician perceives their act is decisive in reporting/non-reporting also became evident in the finding that a large majority of the unreported cases of euthanasia (92.2%) were not labelled as euthanasia by the physician when asked to choose the most appropriate label for the act that they performed. Our study on hypothetical cases in Chapter 7 reconfirmed that the correct labelling of a euthanasia case is the most important factor in determining whether a physician knows the case must be reported and whether they would report the case themselves. Practices that are not labelled or perceived as euthanasia by the physician are not likely to be reported.

The correct labelling of euthanasia is especially problematic when it is performed with opioids or sedatives. Physicians who administer opioids or sedatives as life-ending drugs do not view their act to be euthanasia. Chapter 7 has shown that the case in which the physician ended a patient's life at that patient's request using opioids, which was according to experts with reasonable certainty a euthanasia case, was labelled as euthanasia by only 21% of the physicians and only 18% would report this case themselves, whereas the case in which the physician ended the patient's life using neuromuscular relaxants was labelled as euthanasia by 81% of the physicians and up to 68% of them would report this case themselves. For many physicians, euthanasia thus seems to be related to the use of neuromuscular relaxants and barbiturates. Nonetheless, it is worrying that 19% of the physicians studied in our nationwide survey do not label a case of clear euthanasia performed with neuromuscular relaxants as euthanasia.

Our studies have indicated that there is a considerable distance between the legal definition of euthanasia and physicians' perceptions of what constitutes euthanasia. Especially when opioids are used a grey area between the alleviation of pain and symptoms and euthanasia emerges and confusion about definitions arises. Several possible coinciding hypotheses were proposed in Chapter 6 to explain these finding. These hypotheses can be summarized as follows.
The first hypothesis suggests that when a patient requests that their life be ended and the physician in response disproportionally increases the opioid dose instead of administering neuromuscular relaxants, the distinction between euthanasia and the alleviation of pain and symptom treatment is blurred. The confusion that may arise in such situations may cause physicians not to perceive the act as euthanasia.[35] This hypothesis is supported by the results of our hypothetical case study which show that there is a high degree of confusion and disagreement among physicians about the labelling of the case in which the physician ends the patient's life with opioids. Only one in five physicians labelled this case as euthanasia while most labelled it 'intensification of pain and symptom treatment' (38.5%).

The second hypothesis is one of cognitive dissonance reduction. Some physicians may on the one hand feel reluctant to perform euthanasia or follow the requirements of euthanasia law, while on the other hand they do want to help the patient who requests euthanasia. To reduce this cognitive dissonance and make the act more psychologically acceptable [36], they may choose to use opioids because these drugs are not normally associated with euthanasia. By disguising the act as normal medical practice, whether deliberately or not, they feel they have granted their patient's wish without in their eyes having performed real euthanasia with bolus injection and without having to comply with the requirements of euthanasia law. This hypothesis is supported by data from the interview study. GPs who administered opioids with a life-ending intention felt either very reluctant to perform euthanasia or had a negative opinion about certain procedures of euthanasia law.

The third hypothesis is one of perceived time pressure. In cases in which the patient suffers tremendously, is close to death, and then requests euthanasia, the physician may feel under pressure to help the patient as soon as possible. The process of euthanasia could in such circumstances be perceived as too time-consuming or burdensome. The physician may then prefer to administer opioids instead of neuromuscular relaxants because those drugs are more readily available and there is less control over their distribution compared with neuromuscular relaxants. By disguising the act as alleviation of pain and symptoms, they can proceed with the euthanasia process without having to comply with the stringent, and in their perception time-consuming, procedures of euthanasia law. This hypothesis is supported by data from the death

certificate study. In cases in which the physician had explicitly intended to end the patient's life using opioids the estimated life-shortening effect of the act was usually very limited and in many cases even less than 24 hours. A hypothetical case study conducted in the Netherlands also found that the patient's life expectancy was one of the factors that determined the physicians' labelling of end-of-life practices: cases in which the patient has a very limited life expectancy are less likely to be labelled as euthanasia.[18]

However, it should be remarked that it is possible that some of the cases in the death certificate study that were classified as euthanasia by the researchers were indeed not real cases of euthanasia. It is possible that, instead of having the explicit intention to end the patient's life, physicians may have been convinced that the opioids that they administered primarily to relieve the patient's pain had a certain life-shortening effect. Even though clinical studies have shown that the life-shortening effects of opioids are limited [37-42], the life-shorting effects of opioids are indeed still prone to be overestimated by physicians.[39, 43-46] Having an explicit life-shortening intention could mean these physicians explicitly acted knowing that the patient's life will be shortened. They consequently did not label the case as euthanasia as they did not have the intention to actually end the patient's life. In these cases, the act would indeed classify as alleviation of pain and symptoms and not as euthanasia.[47]

These hypotheses show that labelling of end-of-life practices is inherently complex and difficult. Actual medical practice is hard to contain in a rigid classification scheme and there are obviously a number of psychological complexities underlying physicians' labelling of end-of-life practices and their reporting behavior. These issues make this a very difficult area in which to further increase the transparency of euthanasia practice. More in-depth research is necessary to gain further insight into physicians' motivations, and to better understand how physicians come to classify end-of-life practices. Only then might we be able to start formulating appropriate and concrete interventions to increase societal control in this area. Nonetheless, better information for and education of physicians about the interpretation of euthanasia law and the legal definition of euthanasia could be a good starting point to make physicians more aware of which practices constitute euthanasia and which do not and to remind them that they should report cases of euthanasia, even if they are performed with opioids.

Other factors associated with (non-)reporting

Chapter 7 provides more characteristics of reporting and non-reporting based upon hypothetical cases. Controlling for labelling, other factors were also

significantly associated with whether or not a physician knew a euthanasia case had to be reported and whether they would be willing to report the case themselves, such as a physician's attitude towards euthanasia and towards societal control over euthanasia. Physicians were less likely to know that the hypothetical euthanasia case performed with neuromuscular relaxants had to be reported when they were opposed to euthanasia and were less likely to know that the case had to be reported and to be willing to report it themselves when they were opposed to control over euthanasia. Those physicians who are against euthanasia or control over euthanasia may be less open to information about euthanasia law and the legal reporting obligation than those with a more positive attitude, and will hence be less inclined to report their euthanasia cases in actual practice. The interview study described in Chapter 5 reflects the same idea. There were indications in the interviews that physicians sometimes fail to adhere to the legal requirements because of a negative attitude towards aspects of the law; certain legal requirements such as reporting or consultation were deemed too burdensome or unnecessary.

Physicians from Wallonia especially seem to have a more negative attitude towards societal control over euthanasia and to believe that euthanasia is a private matter between patient and physician that does not need to be controlled by the Federal Review Committee. Such an attitude towards external control over medical practices could be an expression of a tendency towards paternalism among physicians in Belgium, and especially among French-speaking physicians. Such paternalistic attitudes impede societal control over euthanasia, but may be difficult to change nonetheless because they may be deeply rooted in medical culture.

Interestingly, geographic region remained associated with whether a physician knew a euthanasia case had to be reported and whether they would be willing to report the case themselves after controlling for labelling and attitude towards societal control over euthanasia. Compared with physicians from Flanders, Walloon physicians were less aware of the legal reporting requirement and were less willing to report euthanasia cases themselves. This is also reflected in the large regional differences in reported cases of euthanasia to the Federal Review Committee.[1-3] This difference in reporting can thus not only be explained by the fact that physicians from Wallonia are less likely to label euthanasia cases correctly and by their more negative views concerning societal control over euthanasia. Perhaps the geographic differences in reporting could be influenced by a difference in information dissemination between the country regions.[1] Physicians in Wallonia may be less well informed about euthanasia law than their Flemish colleagues. The media coverage on euthanasia has been higher in Flanders and Flemish physicians may have had better access to information from the Netherlands, which has seen a decades-long history of public debate

about euthanasia.[1] Also, training and consultation initiatives, such as the Life End Information Forum (LEIF) are more present in Flanders.[1, 33;48-50]
However, apart from regional differences, the importance of being well informed and having knowledge of the legal requirements cannot be exaggerated. Physicians who did not agree that they were sufficiently informed about euthanasia law, regardless of which region they lived in, were in general less likely to be aware of the reporting obligation.
To conclude, not only correct labelling of end-of-life decisions and drug use are important in explaining reporting behavior, but also physicians' attitudes towards euthanasia and towards societal control over the practice of euthanasia, geographical region and knowledge with regard to legal requirements.

9.4.3 Reported cases of euthanasia

Which patients receive euthanasia and where do they die?

Based on an analysis of all cases of euthanasia reported to the Federal Review Committee between 2002 and 2007, we found that compared with all deaths in the general population euthanasia is more often performed in patients with cancer, patients dying at home, and younger patients. These are the patient groups that have traditionally been found to be more likely to receive euthanasia.[9,10,24,51,52] It is not surprising that patients with cancer are more likely to receive euthanasia than patients with other, more long term chronic illnesses. Cancer is an illness with a reasonably predictable prognosis so these patients may be more aware of the terminal nature of their illness and hence more likely to discuss the end of their life with their physician and to plan ahead.[53,54] Studies have indeed reported that oncologists receive more requests for and have performed euthanasia more often compared with other physicians.[55-57] With long term chronic illnesses such as heart failure, patients are usually ill for longer periods of time. Slow deterioration in health and functional status is typical in patients with chronic illnesses and the timing of death more difficult to predict, which impedes anticipatory discussion about end-of-life matters.[54]
Younger patients are probably more assertive in stating their wishes and more likely to discuss end-of-life matters with their physician than older less emancipated patients. Additionally, physicians may be more inclined to have discussions with younger patients. Patients may further prefer to receive euthanasia in their own home environment, rather than in hospital, where they are surrounded by their loved ones and where euthanasia is performed by their general practitioner with whom the patient often has had a personal and long-established relationship.

Legalization of euthanasia and vulnerable patients

An often expressed fear with regard to euthanasia is that, once it is legalised, the lives of elderly and other vulnerable patients would be more likely to be ended with the assistance of a physician.[59-61] Evidence supporting this fear has not been found in the Netherlands and in Oregon.[62] Our findings do not lead in that direction either, rather to the contrary. Patients of 80 or older were underrepresented among reported euthanasia cases compared to all deaths, even after controlling for diagnosis (elderly patients tend to have cancer less often than younger patients)[53] and place of death (nursing homes tend to have more restrictive policies towards euthanasia). Even older cancer patients dying in a nursing home were underrepresented in euthanasia cases as compared with the general population, although the difference was not statistically significant. Moreover, the number of reported euthanasia cases in this age group did not increase significantly over time. However, in our study with death certificate data we found that cases were significantly less often reported in the group of older patients than in younger patients, probably because physicians use opioids more often in these patients and do not view such acts as euthanasia.[58] Taking this into account older patients are still largely underrepresented. The fact that older patients are underrepresented among euthanasia cases, and that the proportion of older deaths among euthanasia cases and the proportion of care home deaths remained stable over the years studied, shows that our findings on reported cases provide no evidence for the often expressed hypothesis that legalized euthanasia would lead to a slippery slope in which the elderly are at increased risk of euthanasia.

Palliative filter

Flemish Catholic healthcare institutions have wanted to include in law a palliative filter or the requirement to consult a specialized palliative care team in cases where a patient requests euthanasia.[63-65] The aim of the palliative filter was to assure that physicians, nurses and palliative care experts would inform each other about a euthanasia request of a patient and about all palliative care alternatives.[64] Although the palliative filter was not included in the euthanasia law, some of our data on reported cases provide indications that the palliative filter is being applied in practice. According to the requirements of the law, a physician must consult only one other physician in case of a terminally ill patient and two where the patient is not terminally ill. Our data show that physicians involved more physicians than legally required and consulted palliative care teams in the decision-making process in a substantial number of cases, although this is not a legal requirement. The majority of Belgian hospitals have written policies that state that euthanasia is permitted only if certain

palliative care procedures are followed, in addition to those required by law.[63] Our finding that physicians in hospitals more often consulted additional physicians than those at home or in a care home is consistent with this, though we found no difference according to place of death for consultation of palliative teams. The importance of consulting palliative care experts and offering available palliative care options for patients requesting to end their lives cannot be overestimated, but it cannot be denied that there is also a risk involved: the systematic creation of extralegal requirements in practice makes the process of euthanasia more time-consuming and burdensome for already weak and dying patients.[1]

9.4.4 Unreported cases of euthanasia

Are unreported cases of euthanasia conducted with less due care than reported cases?

A majority of the unreported cases of euthanasia were performed with opioids or sedatives, which are not recommended for euthanasia. In the Netherlands, most of the unreported cases of euthanasia were also performed with opioids, albeit that the number of such cases is much smaller in the Netherlands than in Flanders.[10,66] Possibly this can be explained by the fact that, unlike in Belgium, guidelines have been issued with recommendations for the use of appropriate euthanatics in the Netherlands.[67-70] In those guidelines opioids are discouraged as euthanatics because they have an uncertain life-shortening effect and can have very unpleasant side effects for the patient. The fact that such guidelines have not been issued in Belgium after the implementation of the euthanasia law could be a consequence of the fact that the requirement to perform euthanasia with due medical care was not included in the Belgian law as in the Dutch law.[71-73] Performance of euthanasia with due care was considered self-evident as every physician has the duty to act in a medically sensible and careful way.[73] The high number of cases of euthanasia performed with opioids, however, suggests that careful performance of euthanasia is not obvious at all and that official guidelines concerning good performance are called for.

In unreported cases of euthanasia, the drugs were more often administered by a nurse and not according to the requirements of the law than they were in reported cases. That the administering of drugs in euthanasia is often performed by nurses was also found in a study conducted among nurses.[74] Nurses are often involved in the administration of opioids to relieve a patient's suffering. It is likely that because of the blurred line between euthanasia and alleviation of pain and symptoms in these cases, nurses perceived the administration of opioids for euthanasia merely as an extension of the pain and

symptom treatment with opioids that they were already performing.[74] It should be noted that the involvement of nurses in euthanasia performance is legally problematic as the administering of drugs falls under the responsibility of the physician.[72] Nurses who administer euthanatics risk both criminal prosecution and disciplinary measures. Guidelines about good performance of euthanasia could thus not only reduce the use of opioids, but possibly also lower the involvement of nurses in the administering of life-ending drugs by reducing the 'grey area' between euthanasia and the alleviation of pain and symptoms.

In order to stress that the initiative for euthanasia should originate with the patient and to protect the physician who performs euthanasia, it is legally required that the patient's request for euthanasia be put into writing.[72,73,75] In the majority of the unreported cases, however, this requirement was not met. A possible explanation for this came up in the interview study with general practitioners. Euthanasia is an intensive process that requires a great deal of trust between patient and physician. It is possible that because of this relationship of trust, the physician and/or patient believe putting the oral request into writing is not really necessary. It could also be that physicians do not have sufficient knowledge of this legal requirement. Also, in many of the unreported cases the physician did not regard their act as euthanasia and in these cases the physician may not even be aware that the due care requirements of euthanasia law apply.

Other physicians and caregivers specialized in palliative care were significantly less often consulted in unreported cases than in reported cases. Although the consultation of palliative care specialists is not legally required, the consultation of another independent physician is.[72] The strong relationship between a priori consultation of other physicians and the reporting of euthanasia was also found in the Netherlands, where the most important reason for not consulting was that the physician did not intend to report the case.[76,77] A measurement of the reporting rate in a few districts before and after implementation of SCEN, which is a network of consultants that are trained to give expert advice about euthanasia and act as independent second physician in euthanasia requests, showed that the availability of these expert consultants had a positive effect on the reporting rate.[76,77] The expansion of the project afterwards may have contributed to the further increase of the reporting rate in the Netherlands. A similar project, LEIF, exists in Flanders,[50, 78,79] but is not yet as expanded as SCEN. The further development of LEIF in Flanders might play a pivotal role in increasing physicians' knowledge of the requirements in law and may help increase the reporting rate by making expert physicians more readily available for consultation.

9.4.5 Attitudes of physicians

Acceptance of euthanasia and life-ending without explicit patient request

In Chapter 8, it was shown that 90% of those physicians in Belgium who are likely to be involved in the care of dying patients accept the administration of life-ending drugs at the explicit request of a patient with a terminal disease with extreme, uncontrollable pain or other uncontrollable suffering. This high degree of acceptance of euthanasia among Belgian physicians is remarkable, especially considering the limited support for euthanasia among physicians in other countries.[80-82] Acceptance among Belgian physicians has even increased since legalization of the practice. A comparison with a survey conducted in 2002 that included the same statement shows that the acceptance of euthanasia among physicians increased from 78% prior to legalization to 90% in 2009.[83] The practice of euthanasia has also become more prevalent.[24] Euthanasia law and the concurrently enacted laws on palliative care and on patient rights together with the debates that preceded and followed the laws may have led to an increased awareness of the rights of terminally ill patients and to a growing support for self-determination regarding end-of-life decisions.[25] Nowadays, public debates no longer focus on the acceptance of euthanasia, but more on whether or not the current euthanasia law should be broadened to include other patient groups such as minors and persons with dementia. The practice of euthanasia is now also covered in courses and training modules at the level of healthcare institutions, but also on a wider community level of which the training to become a LEIF physician is an example. Nonetheless, the willingness to personally administer drugs to hasten death at the explicit request of a patient was quite a bit lower in our study than the acceptance of euthanasia in general. That should not be surprising as it is probably easier to accept a practice than to actually carry it out and take responsibility for it.

As has been consistently found in studies conducted in other countries, religious beliefs are strong determinants of physicians' attitudes towards euthanasia with religious physicians more often rejecting the practice.[23, 84-88] Our study also found that religious physicians, especially Roman Catholics, were less likely to support the practice of euthanasia than were non-religious physicians, and were more likely to refuse to perform euthanasia themselves. Catholic physicians were indeed less likely to have ever performed euthanasia themselves. Catholic physicians were also less likely to believe that euthanasia can be part of good end-of-life care. The rejection of euthanasia by Catholic physicians is probably related to the fact that in Catholic doctrine euthanasia is considered morally wrong.[89] The influence of the Catholic religion on the stance on euthanasia has also been demonstrated in studies on written policies towards euthanasia in Flemish healthcare institutions. Most Flemish Catholic

hospitals and nursing homes have restrictive policies towards euthanasia; they either completely forbid it or allow it only in very exceptional cases and when palliative procedures, in addition to the legal due care requirements, are followed.[63,64,90-92] Interestingly, we also found that compared to non-religious physicians, Catholic physicians more often agreed that they would rather perform continuous deep sedation at the request of a patient than euthanasia. This could possibly be related to the strong promotion of continuous deep sedation as a morally superior alternative to euthanasia by healthcare professionals opposed to the legalization of euthanasia, which is also reflected in the strong increase in the incidence of continuous deep sedation after the legalization of euthanasia.[24,93]

We found that not only euthanasia but also the practice of life-ending drug use *without* explicit request in terminally ill incompetent patients is largely accepted by physicians in Belgium, even though this practice remains illegal. Particularly physicians with more experience in caring for terminally ill patients were more likely to accept this practice. This seems contradictory as one would expect that those physicians would be more aware of the illegal status of life-ending drug use without request than would be physicians who are less involved in end-of-life care. However, their involvement in caring for the dying might actually explain why they are more accepting of this practice. The constant and personal confrontation with severe suffering that comes with caring for dying patients could make these physicians see life-ending without request in terminally ill incompetent patients as a justifiable option when suffering can no longer otherwise be alleviated. This explanation is supported by a study conducted among nurses that found similar results: also nurses who are directly involved in patient care were more accepting of this practice than were head nurses and nurses working in management functions who are not directly confronted with suffering patients.[94] One would expect that physicians who had followed training in palliative care would then also be more likely to accept the practice of life-ending drug use without request from the patient, but this was not the case in our study; they were in fact less likely to accept this practice, perhaps because of the strong focus in palliative care on patient autonomy at the end of life.[95]

Interestingly, physicians working in Brussels were more likely to accept the practice of life-ending drug use without explicit request in terminally ill incompetent patients than were physicians in Flanders and in Wallonia. A study on end-of-life practices in Brussels found that the incidence of life-ending drug use without explicit request from the patient was also significantly higher in Brussels than in the two other country regions.[96,97] Compared with Flanders, death occurs more often in hospital in Brussels.[98,99] As was found in the study on end-of-life practices in Flanders, the practice of life-ending drug use without

explicit patient request occurs predominantly in hospitals where the focus is more often on curative care than on palliative care.[100] This suggests that anticipatory decision-making occurs less often in hospital, increasing the chance that patients' end-of-life preferences are unknown to the physician when they become unable to express their wishes. Furthermore, physicians in hospitals often have a less personal and long-standing relationship with their patients than do general practitioners. This increases the chance that the patient's personal values and wishes regarding end-of-life care are unknown to the physician. Life-ending without explicit request from the patient thus occurs more often in Brussels than in Flanders or Wallonia and is a more accepted practice there than it is in other parts of the country.

Societal control over the practice of euthanasia

In the nationwide survey among physicians, we found that the need for societal control is generally endorsed by Belgian physicians. However, one in four physicians thinks euthanasia is a private matter that does not need to be controlled by the Federal Review Committee. It was discussed earlier in this part of the dissertation that physicians in Wallonia particularly and, to a lesser degree, in Brussels have this attitude, and how such attitudes are associated with non-reporting of euthanasia cases. With regard to acceptance of societal control over euthanasia, it is also noteworthy that religious physicians, and especially those who are of Roman Catholic affiliation and regularly attend religious ceremonies, are more likely to support control than non-religious physicians. Authors have argued that firm beliefs at the level of life-stance are associated with careful medical practice at the end of life [101], which may be reflected in strongly practicing Roman Catholic physicians' attitudes towards control over the practice of euthanasia. Several studies have also pointed out that the values of society-wide solidarity and responsibility for others are stronger within religiously committed groups than within non-religious groups, which might also explain why committed Roman Catholic physicians are more supportive of the idea of taking responsibility and giving an account to society of their individual actions.[102,103] Alternatively, we can also say that Roman-Catholic physicians are often against euthanasia and do not seem to accept the practice without societal control over it.

Not only committed Roman Catholic physicians but also those who have followed training in palliative care were more supportive of societal control over euthanasia than non-trained physicians. Physicians who are trained in palliative care may be better informed about the reporting requirement and may hence also be more convinced of the need to report euthanasia and bring such far-reaching medical actions into the open for public scrutiny. Alternatively,

physicians who have followed training in palliative care accept the practice of euthanasia as much as other physicians, albeit only under the condition that the practice is being controlled.

Relationship between euthanasia and palliative care

Euthanasia and palliative care are often seen as fundamentally incompatible and proponents of euthanasia and palliative care providers typically have an adversarial relationship to one another regarding the question of euthanasia.[104-107] The Ethics Taskforce of the European Association of Palliative Care explicitly states that 'euthanasia is not part of the responsibility of palliative care.' [108] This view that euthanasia cannot be part of good end-of-life care is shared by many experts in the field of palliative care.[109-110] Some experts also argue that the legalization of euthanasia would have a devastating effect on patient care.[110] However, arguments have also been raised that in Belgium the situation is actually very different; euthanasia and palliative care are rather complementary and synergistic.[111-112] In Belgium, a model of palliative care that includes the possibility of euthanasia has been endorsed by several professional organisations, including the Federation Palliative Care Flanders.[112] We found that the view that euthanasia can be part of good-end-of-life care is generally accepted by physicians in Belgium who are likely to be involved in end-of-life care. Seventy five point two percent of the physicians in our nationwide survey agreed that euthanasia can be part of good end-of-life care and only 10.1% agreed that the euthanasia law impedes the further development of palliative care. Interestingly, physicians trained in palliative care did not hold more negative views towards euthanasia than did non-trained physicians. In fact, trained physicians were actually less likely to perceive legalization as having a negative effect on the development of palliative care and were more likely to have performed euthanasia than were non-trained physicians. These findings are in line with a study that found that euthanasia in Belgium often occurs in the context of multidisciplinary end-of-life care.[113]
The integration of euthanasia and palliative care was also found in our study on reported cases of euthanasia; in one out of three reported cases the physicians had consulted a palliative care team. It thus seems that euthanasia and palliative care are not seen as incompatible by Belgian physicians, but rather as integral aspects of end-of-life care.

9.4.6 General concluding remarks

In this dissertation, several aspects of the reporting of euthanasia cases in medical practice have been described.

In summary, we found that the total number of cases of euthanasia officially reported to the Federal Review Committee has increased every year since legalization and has more than tripled from 235 in 2003 to 822 in 2009. Euthanasia is most often chosen as a last resort at the end of life by younger patients and those with cancer. Patients of 80 years and older are underrepresented among euthanasia cases, and their proportion did not increase over the years studied. Patients receiving euthanasia die more often at home than the general population. The majority of reported cases of euthanasia concerned patients who were deemed to be terminally ill. Euthanasia also occurs in non-terminal patients, some suffering from non-somatic diseases, albeit in very small and not increasing numbers.

Despite the consistent increase in the number of cases of euthanasia reported to the Federal Review, almost half of all cases performed in Flanders are still not being reported. In Chapter 6 we estimated that the reporting rate for euthanasia in Flanders was 52.8% in 2007. The most important reason mentioned for not reporting was that the physician did not perceive their act to be euthanasia. Other reasons for non-reporting, such as that reporting is too much of an administrative burden, that the legal due care requirements had possibly not been met, that euthanasia is a private matter between physician and patient, or because of possible legal consequences were also mentioned, but far fewer times.

Chapters 5, 6 and 7 provided insight into the factors related to non-reporting. How the physician labelled the end-of-life decision was the most important factor explaining non-reporting. Cases that were not labelled as euthanasia were less likely to be reported. However, not only correct labelling of end-of-life decisions was found to be important in explaining reporting behavior, but also physicians' attitudes towards euthanasia and towards societal control over the practice of euthanasia, geographic region and knowledge with regard to legal requirements.

Unreported cases of euthanasia were thus often not labelled as euthanasia by the physician (Chapter 6). In the large majority of unreported cases the euthanasia was performed with opioids and/or sedatives and there was only a very limited life-shortening effect, making these cases less clear-cut than the reported cases of euthanasia in which barbiturates and neuromuscular relaxants were almost always used as euthanatics (Chapters 5 and 6). This points to the existence of a grey zone in which the distinction between euthanasia and alleviation of pain and symptoms is unclear, which hampers societal control over euthanasia. Unreported cases of euthanasia were generally also dealt with less carefully than reported cases: a written request for euthanasia was more often absent, other physicians and care givers specialized in palliative care were

less often consulted, and the life-ending drugs were more often administered by a nurse instead of a physician (Chapters 5 and 6).

In Chapter 8, we found that there is a substantial majority of Belgian physicians supporting the practice of euthanasia for the terminally ill experiencing extreme uncontrollable pain or other uncontrollable symptoms, and most think euthanasia has a place in good end-of-life care. Problematic, however is that one in four physicians is of the opinion that euthanasia is a private matter between patient and physician that does not need to be controlled by the Federal Review Committee. Although studies conducted in other countries often find that physicians trained in palliative care are strong opponents of euthanasia, we found that in Belgium physicians trained in palliative care and those with more experience with caring for the dying were more likely to be involved in euthanasia performance than non-trained physicians and physicians with less experience in caring for the dying.

9.5 Implications and recommendations for policy and practice

One of the most complex and challenging medical and societal debates today surrounds the issue of euthanasia. Questions concerning the possibility of efficient societal control over euthanasia practice and how to safeguard the carefulness of this medical practice are at the forefront of the debates. The studies in this dissertation provide a picture of the medical practice of euthanasia in Belgium with a specific focus on physicians' adherence to legal safeguards and reporting of euthanasia cases. In this section, a number of recommendations will be formulated for policymakers and health care practitioners for the improvement of euthanasia practice and societal control over the practice. The studies in this dissertation show that societal control over the legal practice of euthanasia in Belgium is currently far from complete. With a reporting rate of 52.8%, a lot of work obviously still needs to be done.

In our studies it became apparent that there is a lack of knowledge of what constitutes euthanasia and of the interpretation of the legal requirements and procedures for euthanasia among physicians. Physicians who are unaware of the legal requirements involved in euthanasia are less likely to adhere to them and to report their euthanasia cases. In Belgium, little guidance exists for physicians in understanding and applying euthanasia law, which may create a sense of legal insecurity. Belgium did not have practical experience with euthanasia and a gradual and experience-based development of rules and norms like the Netherlands. Belgian euthanasia law was the result of a quick politically driven process, rather than urged by physician organisations.[114] Also, no relevant jurisprudence on euthanasia exists that could offer guidance in

interpreting the law.[114] Therefore, an important task could be granted to the Federal Review Committee, which could play a much greater role in further clarifying the legal requirements and procedures than it does now. The Federal Review Committee has provided more clarification regarding the issue of physician-assisted suicide and its information brochure for physicians [115] is a good starting point to inform physicians, but perhaps a more systematic approach is needed. Unlike in the Netherlands, there is no systematic feedback from the Federal Review Committee to reporting physicians. Such systematic feedback would substantially increase the transparency of the reporting procedure, could help clarify the interpretation of the legal requirements, and hence improve medical-professional decision-making in euthanasia practice.[116] However, a debate about whether or not physicians would support a non-anonymous reporting procedure with systematic feedback is needed first to determine whether such an intervention could be successful.

Providing more insight into the reasoning behind the Federal Review Committee's assessments would increase the transparency of the working of the Committee and could afford physicians a basis for knowing how to carefully practice euthanasia.[116] This can be done by publishing information in journals which physicians read in large numbers and in the Committee's biennial reports on anonymous individual cases where the way the Committee comes to its conclusions is discussed extensively. Giving insight into the reporting and control procedures and clarifying the interpretation of the legal requirements will give physicians more legal security; this may be conducive to their willingness to report euthanasia.

Finally, by centralizing documents and information regarding euthanasia such as the registration form, euthanasia law, anonymous case reports, and guidelines on careful performance on one specific website, all relevant information for physicians would be more accessible, possibly stimulating physicians to further educate themselves on the topic. The Dutch Review Committees have such a website and it deserves further exploration whether that would be possible in Belgium too.[117] In order to enable the Federal Review Committee to take concrete measures, policy makers must provide financial and logistical support.

Compliance with the legal requirements not only starts with being well informed, but also with acceptance of the requirements as useful and appropriate.[114] Ideally, physicians should be involved in the development of the legal rules concerning euthanasia. In Belgium, this was not the case. Perhaps as a consequence of this, one in four physicians involved in care of the dying in Belgium, and especially in Wallonia, sees euthanasia as a private matter between patient and physician that does not need to be controlled by the Federal Review Committee. This is very problematic because the prospect of efficient societal control is completely dependent on physicians' willingness to report their cases. This suggests that striving for transparency should be integrated with a policy

of persuading physicians of the appropriateness of the requirement to report their cases if it is to lead to an effective policy. Sensitization campaigns, especially targeting physicians in Wallonia, are advised and financial support for such campaigns is needed. LEIF physicians could also play an important role in educating physicians about the usefulness of the legal requirements and stimulate them to comply with them in their own medical practice. Making the LEIF project national, as has been recently decided, is a good starting point for educating and informing physicians in Wallonia as well. It is advised that the LEIF project receives more government funding to enable the project to further expand and that financial support is provided for the physicians wanting to be trained to become a LEIF physician. More media attention for euthanasia in Wallonia could also help sensitize the physicians to the need for societal control in that part of the country where the need for sensitization seems particularly pressing.

Unlike the Dutch law, the Belgian euthanasia law does not include the requirement that the physician should perform euthanasia with due medical care. In the Netherlands, performance with due medical care means among other things that the physician must use the methods, drugs, and dosages described in the Standard Euthanatics from the Royal Dutch Society for the Advancement of Pharmacy (KNMP).[67] During the Parliamentary debates preceding legalization in Belgium, the requirement to perform euthanasia with due medical care was considered superfluous since a physician is always required to act with due medical care.[118] Furthermore, the National Disciplinary Board of Physicians is of the opinion that a physician should be left to decide autonomously which drugs are necessary for euthanasia.[119] As a result, the Federal Review Committee has no statutory ground on which to formulate an advice on the good performance of euthanasia [118] and no guidelines on good performance have been developed. Unfortunately, our studies show that good performance is not obvious and that opioids are still often used to perform euthanasia in Belgium despite their use as euthanatics being clearly dismissed in the medical literature and in Dutch official guidelines.[67-70] Opioids should be reserved for pain and symptom treatment only because they have a doubtful lethal potential and can have unpleasant side effects for the patient.[67-70] Moreover, from our studies it became clear that the use of opioids not only jeopardizes the carefulness of euthanasia practice, but also that their use impedes societal control over euthanasia. Physicians rarely report cases of euthanasia performed with opioids because they do not label such acts as euthanasia. Taking measures to reduce the use of opioids would thus not only improve the quality of euthanasia practice, but is likely also to increase the reporting rate. It is advised that the requirement to perform euthanasia with due care be included in euthanasia law and that clear official guidelines be issued about the appropriate drugs to use (ie barbiturates and neuromuscular

relaxants). Preferably, those guidelines should be drawn up by a medical authority as they will be more acceptable to physicians when their own professional association has worked them out and will be more likely to enjoy the support of informal social control from within the professional group itself than guidelines imposed from outside.[120] The requirements of the guidelines should be taught in future medical training courses and in workshops and seminars. Policymakers must provide financial and logistical support for the organizations willing to provide this training. Additionally to teaching the guidelines, further debate about the effects of opioids in various clinical situations is necessary to raise physicians' awareness of good performance of end-of-life practices and to enhance the level of agreement about what is and what is not euthanasia.

Complete control over the practice of euthanasia has thus not been achieved in Belgium and is probably a utopian ideal. However, because of the legalization of the practice, societal and legal control over euthanasia is now no doubt higher than before legalization and higher than in countries which have not legalized the practice and which have no system for societal control. Legalization of euthanasia in Belgium changed it from being a covert practice in which physicians applied their own standards to a more, albeit not entirely, controlled one. Legal requirements were also introduced to safeguard the carefulness of the practice. What became clear, however, and what is also important to understand for countries considering legalization, is that legalization alone is not sufficient to reach transparency and guarantee careful practice. It seems warranted that legalization, rather than being a final destination, should be seen as a starting point for further debate about standards and guidelines for careful end-of-life practice. To increase the carefulness of euthanasia practice and enhance compliance with the law, a policy should simultaneously be developed to facilitate physicians in dealing adequately with euthanasia requests, including their legal reporting obligation. Such a policy could for instance consist of combining external control by a Review Committee with internal professional control relying on education in medical schools, hospitals and local discussion committees, and on guidelines on good performance developed and enforced by the medical profession itself. Providing adequate support for physicians, in Belgium for example by expanding the LEIF project, could also help physicians deal more carefully with euthanasia and fulfill their legal obligations. It is important, however, that policy makers also provide the necessary financial and logistical means to realize these proposed measures. Finally, transparency is not only needed from physicians, but also from the Review Committee. This can for instance be achieved by providing systematic feedback to all reporting physicians about their medical actions and by making anonymous descriptions of reported cases and considerations when judging these reports in public like in the Netherlands.

By so doing, the Review Committee could play an important role in clarifying the interpretation of the legal requirements, in improving medical-professional decision-making, and ultimately in stimulating physicians to report their cases.

9.6 Further research

There is a noticeable lacuna in the current research on reporting of euthanasia in relation to Wallonia. Although it is known that only about 15 to 20% of all cases of euthanasia reported between 2002 and 2007 to the Federal Review Committee were reported by French-speaking physicians, a reporting rate for Wallonia could not be estimated because recent death certificate data are not available for Wallonia. As soon as recent data become available, a death certificate study should be conducted in that part of the country too. Although our nationwide survey among physicians provides important insights into the situation in Wallonia, conclusive explanations for the disproportionately low number of reported cases by French-speaking physicians cannot yet be formulated.

In our studies we found that labelling plays a key part in explaining non-reporting of euthanasia cases. Future research should delve deeper into how physicians come to label end-of-life practices and which factors are important in their labelling. Also, we found that physicians in Wallonia label the same end-of-life practices differently from Flemish physicians. They are for instance more likely to label a prototypical case of euthanasia with neuromuscular relaxants as 'alleviation of pain and symptoms' or 'palliative/terminal sedation' than Flemish physicians. Explanations for this difference in labelling between Walloon and Flemish physicians should also be further explored.

In Chapter 5 we found that there is a considerable gap between the legal definition of euthanasia and what physicians consider to be euthanasia. Several hypotheses were proposed to explain the mechanisms behind this finding. In further research these hypotheses should be tested empirically. Testing these hypotheses may provide considerable insight into the psychological complexities underlying physicians' labelling of end-of-life practices and their reporting behavior. Also, physicians' motivations for using opioids for euthanasia should be further investigated as the use of opioids is highly associated with incorrect labelling of euthanasia.

What has also been left unexplored in this dissertation is the control procedure by the Federal Review Committee. Currently, the working of the Committee remains a black hole. How does the Committee assess reported cases? What is the reasoning behind their judgments? Do physicians on the Committee judge

differently from the lawyers or the members with experience in the field of palliative care? How does the Committee interpret the legal due care requirements? These are questions that still need answers. What could also be investigated in future studies are the experiences of physicians with reporting of euthanasia cases and with the Federal Review Committee.

A final recommendation for future studies concerns physicians' attitudes towards euthanasia, towards euthanasia law and-towards societal control over euthanasia, which should be further investigated with qualitative research methods. More in-depth insight is needed to understand these attitudes, for attitudes are very complex and difficult to understand when measured solely on a quantitative scale. For example, in our nationwide survey many physicians agreed with the statement that euthanasia is a private matter between patient and physician that does not need to be controlled by the Federal Review Committee. This is an important finding which, however, raises further questions. Why do physicians have this attitude, and if they think euthanasia should not be controlled by the Federal Review Committee, what kind of control over their actions, if any, would be acceptable for them? Further research should focus on examining whether and how attitude change in this area could be effected and on exploring ways in which societal control may become more acceptable to all physicians.
Furthermore, our study assessed the attitude of physicians towards euthanasia in terminally ill patients. The law on euthanasia is also applicable to non-terminal patients and physicians' attitudes towards euthanasia in non-terminal patients have not been investigated in this dissertation.

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SAMENVATTING VAN DE BELANGRIJKSTE BEVINDINGEN

Inleiding

Potentieel levensverkortende beslissingen van artsen rond het levenseinde van patiënten nemen in de medische praktijkvoering een belangrijke plaats in. Euthanasie, gedefinieerd als 'het opzettelijk levensbeëindigend handelen door een ander dan de betrokkene, op dienst expliciete verzoek' gaat naar schatting in 1.9% van alle sterfgevallen aan het overlijden vooraf. Hoewel euthanasie ten opzichte van de andere medische beslissingen aan het levenseinde qua incidentie slechts een marginale positie inneemt, is deze categorie van medische beslissingen zo ingrijpend dat de wetgever in 2002 besloot om hiervoor een wettelijke regeling te treffen. Daarmee is België momenteel, samen met Nederland en Luxemburg, één van de weinige landen in heel de wereld waar euthanasie wettelijk mogelijk is, weliswaar onder strikte voorwaarden. De wet betreffende de euthanasie geeft de arts de mogelijkheid om legaal in te gaan op de vraag naar euthanasie van de patiënt voor zover voldaan is aan de in de wet omschreven zorgvuldigheidsvoorwaarden en procedures.

De arts die euthanasie toepast dient zich ervan te verzekeren dat de patiënt een meerderjarige of ontvoogde minderjarige is, die handelingsbekwaam en bewust is op het ogenblik van zijn of haar verzoek. De arts moet bovendien nagaan dat het verzoek vrijwillig, overwogen en herhaald is, en niet tot stand gekomen is als gevolg van enige externe druk. Het verzoek om euthanasie moet bovendien op schrift gesteld worden. De wet schrijft verder voor dat de patiënt zich in een medisch uitzichtloze toestand van aanhoudend en ondraaglijk fysiek of psychisch lijden moet bevinden, dat niet gelenigd kan worden, en dat het gevolg is van een ernstige en ongeneeslijke, door ongeval of ziekte veroorzaakte aandoening. De arts moet vooraf en in alle gevallen de patiënt inlichten over zijn gezondheidstoestand en zijn levensverwachting, met de patiënt overleg plegen over zijn verzoek tot euthanasie en met hem de eventueel resterende therapeutische mogelijkheden bespreken. De arts moet met de patiënt tot de overtuiging komen dat er geen redelijke andere oplossing is en zich verzekeren van het duurzaam karakter van het verzoek. Verder dient hij een andere, onafhankelijke arts te raadplegen en hem op de hoogte te brengen van de redenen voor deze raadpleging. De arts moet het verzoek van de patiënt ook bespreken met het verplegend team en, indien de patiënt dit wenst, met de naasten.
Indien de patiënt kennelijk niet binnen afzienbare termijn zal overlijden (niet terminaal ziek is), stelt de wet nog twee bijkomende eisen. De arts moet naast het verplicht consulteren van een tweede arts ook nog een derde arts raadplegen, die ofwel een specialist is in de aandoening waaraan de patiënt lijdt

of een psychiater, en moet een maand laten verlopen tussen het schriftelijk verzoek van de patiënt en het uitvoeren van de euthanasie.

Euthanasie is een uitzonderlijke handeling en vereist een vorm van maatschappelijke controle om misbruiken te voorkomen. De wetgever heeft er daarom voor gekozen om de arts te verplichten om ieder geval van euthanasie te melden aan de door de wet opgerichte Federale Controle- en Evaluatiecommissie voor euthanasie. Deze Commissie heeft onder andere als taak om aan de hand van de door de artsen ingediende registratiedocumenten te controleren of zij bij de uitvoering van de euthanasie aan de bovenvernoemde wettelijke vereisten hebben voldaan. Sinds de inwerkingtreding van de wet op 22 september 2002 zijn artsen verplicht om ieder geval van euthanasie te melden aan de commissie. De hoofddoelen van de meldingsprocedure zijn, naast zorgvuldig medisch handelen bevorderen, onder meer openheid creëren rond euthanasie en uniforme registratie van euthanasiegevallen in heel België mogelijk maken.
Het succes van de meldingsprocedure hangt uiteraard grotendeels af van de mate waarin artsen bereid zijn om euthanasie te melden.

Onderzoeksvragen

In dit proefschrift worden de melding van euthanasie door artsen en hun naleving van de wettelijke zorgvuldigheidsvoorwaarden en procedures onderzocht in België. Daarnaast worden ook de attitudes van artsen tegenover het gebruik van levensbeëindigende middelen en tegenover de euthanasiewet bestudeerd. Volgende onderzoeksvragen worden beantwoord:

1. Wat houden de meldings-, controle- en evaluatieprocedures voor euthanasie in in België en in Nederland? Wat zijn de gelijkenissen en verschillen in de procedures in beide landen?
2. Wat zijn de mogelijke implicaties van de verschillen in de procedures voor een veilige en controleerbare euthanasiepraktijk?
3. Wat zijn de kenmerken van de gemelde euthanasiegevallen in België? Is er een verandering in de kenmerken doorheen de jaren? Wat zijn de gelijkenissen en verschillen in de kenmerken van gemelde euthanasiegevallen in België en in Nederland?
4. In welke mate melden de artsen hun euthanasiegevallen aan de Federale Controle- en Evaluatiecommissie voor euthanasie (meldingspercentage)?
5. Welke redenen geven artsen voor het niet melden van euthanasiegevallen, en welke factoren hangen samen met melden en niet-melden van euthanasiegevallen?

6. In welke mate houden artsen zich in de praktijk aan de wettelijke zorgvuldigheidsvoorwaarden en procedures? Welke redenen geven artsen om zich niet aan deze zorgvuldigheidsvoorwaarden en procedures te houden?
7. Zijn er verschillen tussen gemelde en niet-gemelde euthanasiegevallen wat betreft kenmerken van zorgvuldigheid?
8. Wat zijn de attitudes van Belgische artsen tegenover het gebruik van levensbeëindigende middelen en tegenover de euthanasiewet? Welke factoren hangen samen met deze attitudes?
9. Welke factoren voorspellen of een arts ooit zelf al dan niet euthanasie uitgevoerd heeft?

Methode

Om deze onderzoeksvragen te beantwoorden, werd gebruik gemaakt van vier verschillende databronnen: (1) databestanden van de Federale Controle -en Evaluatiecommissie voor euthanasie en van de Regionale Toetsingscommissies Euthanasie met gegevens over alle gemelde euthanasiegevallen in België en Nederland tussen 2002 en 2007; (2) de sterfgevallenstudie; (3) de SENTI-MELC interview studie; en (4) een landelijk survey onderzoek bij artsen. De verschillende studies en methoden worden op verschillende plaatsen in dit proefschrift uitgebreid beschreven. In alle studies werd de anonimiteit van artsen en patiënten uiteraard verzekerd.

Het onderzoek werd uitgevoerd in het kader van een groter onderzoeksproject, het '**M**onitoring the **Q**uality of **E**nd-of-**L**ife **C**are' of MELC project, dat werd gefinancierd door het Instituut voor de aanmoediging van Innovatie door Wetenschap en Technologie in Vlaanderen (IWT-Vlaanderen).

Resultaten

De meldings-, controle- en evaluatieprocedures voor euthanasie in België en Nederland

De meldings- en controlemechanismen zijn vrij gelijklopend in België en Nederland aangezien de Belgische wetgeving in grote mate gebaseerd is op het Nederlandse model. Toch zijn er enkele belangrijke verschilpunten.

Zowel in België als in Nederland zijn artsen wettelijk verplicht om elk euthanasiegeval dat zij uitvoeren aan de hand van een registratiedocument te melden aan een Commissie. In België moeten artsen het ingevulde

registratiedocument rechtstreeks opsturen naar de Federale Controle- en Evaluatiecommissie. In Nederland moeten artsen de lijkschouwer op de hoogte brengen van het overlijden, zoals het geval is bij elk onnatuurlijk overlijden. De Nederlandse artsen moeten tevens een ingevuld registratiedocument samen met nog andere documenten zoals het verslag van de tweede wettelijk verplicht geconsulteerde arts bezorgen aan de lijkschouwer. De lijkschouwer onderzoekt op zijn beurt het lichaam van de overledene en gaat na hoe de euthanasie werd uitgevoerd en welke middelen werden gebruikt. De lijkschouwer stelt een verslag op van zijn bevindingen en stuurt dit verslag, samen met het registratiedocument en de andere documenten naar één van vijf regionale toetsingscommissies.

Het Nederlandse registratiedocument is uitgebreider en bevat meer open vragen dan het Belgische document. In tegenstelling tot het Nederlandse registratiedocument is het Belgische anoniem.

In België bestaat er één Federale Controle- en Evaluatiecommissie, terwijl er in Nederland vijf regionale toetsingscommissies werden ingesteld. De Commissies fungeren als buffer tussen de artsen en het gerecht. In beide landen gaan de Commissies na of de arts bij de uitvoering van de euthanasie alle wettelijke zorgvuldigheidsvoorwaarden en procedures heeft nageleefd. Wanneer de Commissie oordeelt dat de wet werd nageleefd, dan is de zaak afgerond. Indien er twijfel bestaat over naleving van de wet dan kan het dossier doorgestuurd worden voor verder onderzoek: in België naar de Procureur des Konings en in Nederland naar het College van Procureurs Generaal en de Regionale Inspecteur voor de Volksgezondheid. In principe worden de gemelde euthanasiegevallen in België anoniem behandeld. Enkel wanneer de commissieleden twijfelen of de arts de euthanasiewet heeft nageleefd, kan ze beslissen om de anonimiteit van het registratiedocument op te heffen en de arts te contacteren voor bijkomende informatie of verduidelijking. De Nederlandse toetsingscommissies kunnen de artsen rechtstreeks contacteren waardoor rechtstreekse dialoog mogelijk is. Elke meldende arts in Nederland ontvangt steeds van de toetsingscommissie feedback over zijn of haar handelen. In België is dit wegens de anonimiteit van de meldingsprocedure niet het geval.

Zowel in België als in Nederland zijn de Commissies wettelijk verplicht om een verslag op te stellen over de gemelde euthanasiegevallen om het publiek te informeren, de euthanasiewet te evalueren op haar praktische toepassing, en eventueel voorstellen te doen voor aanpassing van de wet. In België stelt de Commissie tweejaarlijks zulk een rapport op dat zij rechtstreeks naar het Parlement stuurt. In Nederland rapporteren de toetsingscommissies jaarlijks gezamenlijk aan de Minister van Volksgezondheid, Welzijn en Sport, en aan de Minister van Justitie, die op hun beurt rapporteren aan het Parlement.

Kenmerken van gemelde euthanasiegevallen

Om na te gaan hoe de euthanasiewet door artsen in de praktijk wordt toegepast, werd er in eerste instantie een studie uitgevoerd naar euthanasiegevallen die door artsen gemeld werden aan de Federale Controle- en Evaluatieprocedure. Voor deze studie werden de gegevensbestanden van alle gemelde euthanasiegevallen sinds de inwerkingtreding van de euthanasiewet op 22 september 2002 tot en met eind 2007 opgevraagd bij de Commissie. Op basis van een grondige analyse van de registratiebestanden van gemelde euthanasiegevallen die we van de Commissie mochten ontvangen, stelden we vast dat het aantal gemelde euthanasiegevallen elk jaar stijgt: van 235 in 2003, 347 in 2004, 388 in 2005, 428 in 2006, tot 495 in 2007. De overgrote meerderheid van de gevallen (83,1%) werd door Nederlandstalige artsen gemeld.

Van alle gemelde euthanasiegevallen was 53% man en 47% vrouw. De meeste patiënten (79%) die euthanasie verkregen waren tussen de veertig en negenenzeventig jaar oud. Euthanasie komt zelden voor bij patiënten van 80 jaar of ouder: slechts 18 procent van de bestudeerde gevallen betrof mensen ouder dan tachtig en hun aantal is niet significant toegenomen in de loop van de jaren.
De euthanasie vond in iets meer dan de helft van alle gevallen plaats in het ziekenhuis en in 42% van alle gevallen thuis. In het rusthuis komt euthanasie maar zelden voor. Wanneer we de gemelde euthanasiegevallen op die kenmerken vergeleken met gans de sterftepopulatie in Vlaanderen en Brussel (gegevens voor Wallonië waren niet beschikbaar), dan zagen we dat mensen jonger dan 80 jaar onder de euthanasiegevallen oververtegenwoordigd zijn (82% versus 50%), terwijl 80 plussers net ondervertegenwoordigd zijn (18% versus 50%). Ook sterven mensen die euthanasie verkrijgen proportioneel vaker thuis dan het geval is in de algemene sterftepopulatie (42% versus 22%).

De meeste patiënten die euthanasie verkregen hadden kanker (83%), terwijl slechts een kleine minderheid een andere diagnose had zoals een neuromusculaire aandoening of een cardiovasculaire aandoening (zie tabel 2). In de algemene sterftepopulatie is die verhouding net omgekeerd. Ongeveer één op vier van alle overlijdens is het gevolg van kanker, terwijl de meeste mensen die sterven een andere doodsoorzaak kennen.

Voor bijna alle gemelde gevallen (96%) gaf de arts aan dat er sprake was van fysiek lijden. Psychisch lijden werd voor minder, maar voor nog steeds een aanzienlijk deel van de gevallen (68%) gerapporteerd. Wanneer er sprake was van fysiek lijden dan betrof het in de meeste gevallen pijn of cachexie/uitputting. Wanneer er sprake was van psychisch lijden dan betrof het

meestal verlies van waardigheid/wanhoop. De meeste patiënten waren volgens de meldende arts terminaal ziek (93%). Niet-terminaal zieke patiënten maakten slechts 7% uit van alle gemelde gevallen. Deze patiënten leden voornamelijk aan andere ziekten dan kanker zoals progressieve of niet-progressieve neuromusculaire aandoeningen (52%) of cardiovasculaire aandoeningen (9%). Hun aantal is in de loop van de jaren niet significant toegenomen.

Artsen hadden in alle gevallen een tweede onafhankelijke arts geconsulteerd, zoals de euthanasiewet voorschrijft. Deze tweede arts was meestal specialist of huisarts. Voor patiënten die volgens de arts (nog) niet terminaal ziek zijn, dient hij of zij volgens de euthanasiewet nog een derde onafhankelijke arts te consulteren. Deze was voor de gemelde euthanasiegevallen meestal psychiater. In ruim één op drie van de gemelde euthanasiegevallen had de arts nog bijkomende artsen of een palliatief team geconsulteerd. Deze consultaties zijn niet wettelijk verplicht. De uitvoering van de euthanasie gebeurde bijna steeds door toediening van een barbituraat al dan niet in combinatie met een spierverslapper. Morfine werd voor de uitvoering van de euthanasie slechts in 1% van alle gemelde gevallen gebruikt.

Een vergelijking van de kenmerken van gemelde euthanasiegevallen in België en in Nederland toonde aan dat er in Nederland veel meer euthanasiegevallen gemeld werden tussen 2002 en 2007 dan in België (10319 versus 1917). Er waren geen significante verschillen in geslachts- en leeftijdsverdeling van gemelde gevallen in beide landen. Hoewel in beide landen de meeste patiënten leden aan kanker, was het aandeel patiënten dat aan neuromusculaire ziekten leed groter in België dan in Nederland (8.3% vs. 3.9%). Een ander opvallend verschil was dat patiënten die euthanasie verkregen in Nederland veel vaker thuis overlijden dan in België (81% vs. 42%) en in België veel vaker in het ziekenhuis dan in Nederland (52% vs. 9%). In Nederland waren alle gemelde gevallen van euthanasie gebaseerd op een actueel mondeling verzoek van een competente patiënt, terwijl in België 2.1% van alle gevallen gebaseerd was op een voorafgaande schriftelijke euthanasieverklaring van een patiënt in een onomkeerbare coma of een persistente vegetatieve toestand.

Meldingspercentage, redenen voor niet-melden en factoren geassocieerd met melden/niet-melden van euthanasiegevallen

Op basis van een grootschalige sterfgevallenstudie werd geschat hoeveel euthanasiegevallen er in 2007 door artsen in Vlaanderen werden uitgevoerd en in welke mate deze artsen hun euthanasiegevallen melden. Het totaal aantal euthanasiegevallen dat in de studie werd teruggevonden was 137. Geëxtrapoleerd betekent dit dat in 2007 in Vlaanderen ongeveer 1040

euthanasiegevallen werden uitgevoerd. Dit komt overeen met een incidentie van 1.9%. De artsen gaven in de vragenlijst aan dat ze 53% van alle uitgevoerde euthanasiegevallen gemeld hadden aan de Commissie. Uit het onderzoek bleek dat zowel huisartsen als specialisten even vaak hun euthanasiegevallen meldden.

Aan artsen die aangaven dat ze hun handelen niet gemeld hadden, werd in de sterfgevallenstudie ook gevraagd wat daarvoor de redenen waren. Voor 77% van de niet-gemelde euthanasiegevallen gaven de artsen aan dat ze hun handelen niet als euthanasie beschouwden; voor 18% van de gevallen gaven ze als reden dat melden een te grote administratieve rompslomp is; voor 12% gaven ze aan dat mogelijk niet aan alle wettelijke zorgvuldigheidscriteria was voldaan; voor 9% dat euthanasie een zaak is van arts en patiënt, en voor 2% uit vrees voor mogelijke juridische gevolgen (meerdere antwoorden waren mogelijk).

Uit verschillende studies beschreven in dit proefschrift blijkt dat niet-melden van euthanasie sterk samenhangt met hoe een arts zijn of haar handelen benoemt. In de sterfgevallenstudie bleek dat gevallen die door de arts ook als euthanasie benoemd werden in 93% van de gevallen ook gemeld werden, terwijl dit percentage sterk lager was voor gevallen waarbij de arts zijn of haar handeling niet als euthanasie benoemde maar als palliatieve/terminale sedatie of niet-behandelbeslissing. Deze handelingen werden in respectievelijk 6% en 25% van de gevallen gemeld.
Uit de hypothetische casussenstudie op basis van de artsensurvey bleek ook dat hoe een arts zijn of haar handeling benoemt, samenhangt met kennis van melden en bereidheid om zelf te melden. Artsen die een hypothetische euthanasiecasus ook als euthanasie benoemden, hadden veel meer kans om te weten dat de casus gemeld zou moeten worden en waren ook vaker bereid om de casus zelf te melden in het geval ze de handeling beschreven in de casus zelf uitgevoerd zouden hebben dan artsen die de casus niet als euthanasie benoemden.
Artsen die in Vlaanderen wonen, die volgens eigen inschatting voldoende op de hoogte zijn van de inhoud van de euthanasiewet, en zij die een positieve attitude hebben tegenover maatschappelijke controle op de euthanasiepraktijk hebben meer kans om een euthanasiecasus als euthanasie te benoemend dan artsen uit Wallonië of Brussel, artsen die volgens eigen inschatting minder goed op de hoogte zijn van de inhoud van de wet en artsen met een negatieve attitude tegenover maatschappelijke controle.

Hoe een arts een euthanasiecasus benoemt, blijkt samen te hangen met de middelen die gebruikt worden om de euthanasie uit te voeren. Uit de hypothetische casussenstudie bleek dat 80.9% van de artsen een casus waarin de arts euthanasie uitvoert met barbituraten en spierverslappers als euthanasie

benoemt, terwijl slechts 20.5% van de artsen een euthanasie met morfine benoemt als euthanasie. Uit de sterfgevallenstudie was ook al gebleken dat het meldingspercentage voor euthanasiegevallen uitgevoerd met barbituraten en spierverslappers veel hoger is dan het meldingspercentage voor euthanasiegevallen uitgevoerd met opiaten of andere voor euthanasie niet-aanbevolen middelen (92.9% vs. 4.8%).

Uit de casussenstudie bleek dat niet enkel hoe een arts een handeling benoemt, maar ook andere factoren samenhangen met een hogere waarschijnlijkheid dan men weet dat een casus gemeld moet worden. Die factoren zijn: vrouw zijn, in Vlaanderen wonen, naar eigen inschatting voldoende geïnformeerd zijn over de inhoud van de euthanasiewet, en een positieve attitude hebben tegenover euthanasie en tegenover maatschappelijke controle op de euthanasiepraktijk. Behalve attitude tegenover euthanasie hingen dezelfde factoren ook samen met bereidheid om zelf een euthanasiecasus te melden.

Naleving van de wettelijke zorgvuldigheidsvoorwaarden en procedures

Op basis van gegevens van de SENTI-MELC interview studie werd de mate waarin huisartsen in België de wettelijke zorgvuldigheidsvoorwaarden en procedures in de praktijk naleven bestudeerd. Uit de negen interviews bleek dat de meeste van de geïnterviewde huisartsen op de hoogte waren van de zorgvuldigheidsvoorwaarden en procedures en zich er ook aan probeerden te houden in de praktijk. Aan de substantiële voorwaarden met betrekking tot het verzoek tot euthanasie en de medische situatie van de patiënt was in alle negen onderzochte gevallen voldaan. Alle patiënten hadden een vrijwillig en weloverwogen verzoek tot euthanasie gedaan, en alle patiënten waren in een medisch uitzichtloze situatie. In tegenstelling tot de substantiële voorwaarden werden de procedurele consultatie – en meldingsvoorwaarden in sommige gevallen niet nageleefd: in drie gevallen consulteerde de arts geen tweede onafhankelijke arts en in vier gevallen was het geval niet gemeld.

Redenen die vermeld werden om geen tweede arts te consulteren waren dat de arts vond dat zulk een consultatie niet noodzakelijk was omdat het in hun ogen niet echt om een euthanasiegeval in wettelijke zin ging (n=2); omdat de arts vond dat de wettelijke consultatieverplichting te zwaar en niet nuttig was, en het aan arts en patiënt was om te beslissen over de euthanasie (n=1). Gevallen van euthanasie werden minder vaak gemeld als de arts ze niet als euthanasie benoemde, wanneer opiaten gebruikt werden om de euthanasie uit te voeren, en wanneer de arts geen tweede onafhankelijke arts geconsulteerd had. De wettelijke zorgvuldigheidsvoorwaarden werden minder vaak nageleefd in de niet-gemelde dan in de gemelde gevallen.

Een vergelijking van gemelde en niet-gemelde euthanasiegevallen

De sterfgevallenstudie liet ons toe om gemelde en niet-gemelde euthanasiegevallen met elkaar te vergelijken op een aantal zorgvuldigheidskenmerken. Niet-gemelde euthanasiegevallen worden doorgaans minder zorgvuldig behandeld door de arts dan de euthanasiegevallen die wel gemeld worden. Een mondeling en schriftelijk verzoek zoals de euthanasiewet voorschrijft waren in 73% van de gemelde gevallen aanwezig, terwijl bij de niet-gemelde gevallen dit schriftelijk verzoek meestal ontbrak (88% enkel mondeling verzoek en 9% zowel mondeling als schriftelijk verzoek). De beslissing voor euthanasie werd bij niet-gemelde euthanasiegevallen veel minder vaak besproken met anderen. In slechts 55% van de niet-gemelde gevallen werden andere artsen geconsulteerd, terwijl er bij gemelde gevallen in 72% overleg was geweest met andere artsen. Ook specialisten in palliatieve zorg en verpleegkundigen werden veel minder vaak geconsulteerd bij niet-gemelde euthanasiegevallen.

Artsen die hun euthanasiegeval meldden gebruikten in de meeste gevallen barbituraten al dan niet in combinatie met spierverslappers om de euthanasie uit te voeren. Dit is volgens de medische literatuur en volgens officiële richtlijnen van de KNMP uit Nederland ook de meest aangewezen methode om euthanasie uit te voeren. Artsen die hun euthanasiegevallen niet meldden, gebruikten vaker andere middelen zoals opiaten of sedativa. Deze middelen zijn niet aangeraden om euthanasie uit te voeren. Het levensverkortend effect van morfine wordt betwijfeld en hoge dosissen morfine kunnen ongewenste nevenverschijnselen geven voor de patiënt. Waar het levensbeëindigend middel bij gemelde euthanasiegevallen steeds toegediend werd door een arts, zoals vereist is volgens de euthanasiewet, gebeurde dit bij de niet-gemelde euthanasiegevallen in 41% van de gevallen door een verpleegkundige.

Attitudes van Belgische artsen tegenover euthanasie en de euthanasiewet

Van de artsen die deelnamen aan de landelijke survey was negen op de tien het eens met de stelling dat het toedienen van levensbeëindigende middelen op expliciet verzoek van de patiënt aanvaardbaar is bij patiënten met een terminale ziekte met extreme, oncontroleerbare pijn of ander oncontroleerbaar lijden. Ook de stelling dat levensbeëindiging op verzoek van de patiënt kan deel uitmaken van goede zorg aan het levenseinde werd door 75% van de bestudeerde artsen ondersteund. Opvallend ook was dat meer dan de helft (60%) van de artsen het ook eens was met de stelling dat indien een ongeneeslijke zieke ondraaglijk lijdt en niet in staat is om zelf beslissingen te nemen, de arts (met het verzorgend team) zou moeten kunnen beslissen om

levensbeëindigende middelen toe te dienen. De helft van de artsen was ook eerder bereid om continue diepe sedatie toe te passen op verzoek van de patiënt dan tot het toedienen van levensbeëindigende middelen op verzoek van de patiënt.

Achtenzestig procent van de artsen vindt dat maatschappelijke controle op de euthanasiepraktijk noodzakelijk is, maar 27% vindt dat euthanasie een zaak is van de arts en de patiënt waar de Controle- en Evaluatiecommissie niet moet op toezien. Slechts 10% van de artsen denkt dat de euthanasiewet de verdere uitbouw van de palliatieve zorg verhindert.

Rooms-katholieke artsen waren het in vergelijking met niet-religieuze artsen minder vaak eens met de stelling dat toedienen van levensbeëindigende middelen op expliciet verzoek van de patiënt aanvaardbaar is bij patiënten met een terminale ziekte met extreme, oncontroleerbare pijn of ander oncontroleerbaar lijden en met de stelling dat indien een ongeneeslijke zieke ondraaglijk lijdt en niet in staat is om zelf beslissingen te nemen, de arts (met het verzorgend team) zou moeten kunnen beslissen om levensbeëindigende middelen toe te dienen. Rooms-katholieke artsen gingen ook minder vaak akkoord met de stelling dat euthanasie deel kan uitmaken van goede zorg aan het levenseinde dan niet-religieuze artsen. Artsen uit Wallonië waren in vergelijking met hun Vlaamse en Brusselse collega's minder vaak bereid om zelf euthanasie uit te voeren en waren het er vaker mee eens dat ze eerder bereid zouden zijn om continue diepe sedatie toe te passen dan euthanasie. Waalse artsen vonden ook minder vaak dat euthanasie deel kan uitmaken van goede zorg aan het levenseinde. Artsen uit Brussel op hun beurt, waren het vaker eens met de stelling dat indien een ongeneeslijke zieke ondraaglijk lijdt en niet in staat is om zelf beslissingen te nemen, de arts (met het verzorgend team) zou moeten kunnen beslissen om levensbeëindigende middelen toe te dienen dan artsen van Vlaanderen of Wallonië. Het al dan niet formele vorming in palliatieve zorg genoten hebben, had geen invloed op de attitude van artsen tegenover euthanasie. Wel was het zo dat artsen die aangaven dat ze nooit formele vorming in palliatieve zorg genoten hadden en dat artsen die in het afgelopen jaar tien of meer patiënten in de terminale fase verzorgd hadden het vaker eens waren met de stelling dat indien een ongeneeslijke zieke ondraaglijk lijdt en niet in staat is om zelf beslissingen te nemen, de arts (met het verzorgend team) zou moeten kunnen beslissen om levensbeëindigende middelen toe te dienen dan artsen die wel formele vorming in palliatieve zorg genoten hadden of die minder dan tien patiënten in de terminale fase verzorgd hadden.

Met betrekking tot melding en controle op de euthanasiepraktijk was het opmerkelijk dat Rooms- Katholieke artsen in vergelijking met niet-religieuze

artsen het minder vaak eens waren met de stelling dat de euthanasiewet bijdraagt tot de zorgvuldigheid van het medisch handelen aan het levenseinde door artsen. Zij gingen wel vaker akkoord met de stelling dat maatschappelijke controle op de euthanasiepraktijk noodzakelijk is en met de stelling dat het melden van euthanasie bijdraagt tot de zorgvuldigheid van het medisch handelen aan het levenseinde door artsen. Waalse en Brusselse artsen waren het vaker dan Vlaamse artsen eens met de stelling dat euthanasie een zaak is van de arts en de patiënt waar de Controle- en Evaluatiecommissie niet moet op toezien. Oudere artsen, huisartsen, artsen die geen enkele vorm van formele vorming in palliatieve zorg genoten hadden en Rooms- Katholieke artsen waren het vaker eens met de stelling dat de euthanasiewet de verdere uitbouw van de palliatieve zorg verhindert dan jongere artsen, specialisten, artsen die wel formele vorming in palliatieve zorg genoten hadden en niet-religieuze artsen. Artsen die geen formele vorming in palliatieve zorg genoten hadden waren ook vaker van mening dat euthanasie een zaak is van de arts en de patiënt waar de Controle- en Evaluatiecommissie niet moet op toezien en waren het er minder vaak mee eens dat maatschappelijke controle op de euthanasiepraktijk noodzakelijk is dan artsen die wel vorming genoten hadden.

Eén op de vijf onderzochte artsen had ooit al eens zelf euthanasie toegepast. Niet-religieuze artsen hadden meer kans om ooit al eens zelf euthanasie uitgevoerd te hebben dan Rooms- Katholieke artsen en gelovige artsen zonder specifieke religie. Andere factoren die geassocieerd zijn met een grotere kans om ooit zelf euthanasie uitgevoerd te hebben zijn specialist zijn: ouder zijn, formele vorming in palliatieve zorg genoten hebben, en tijdens het afgelopen jaar patiënten in de terminale fase verzorgd hebben.

Discussie

Het meldingspercentage

In 2007 was het meldingspercentage voor euthanasie in Vlaanderen 52.8%. Aangezien dit de eerste keer is dat het meldingspercentage geschat is en geen incidentieschattingen van euthanasie beschikbaar zijn voor de andere jaren sinds de euthanasiewet in werking trad, weten we niet of dit nu een stijging dan wel een daling van het meldingspercentage betekent. Wat we wel weten is dat het aantal bij de Commissie gemelde euthanasiegevallen elk jaar spectaculair stijgt. Hoewel de incidentie van euthanasie ook gestegen is van 1.1% in 1998 tot 1.9% in 2007, doet deze spectaculaire stijging van het aantal meldingen toch vermoeden dat ook het meldingspercentage gestegen is.

De jaarlijkse stijging van het aantal gemelde euthanasiegevallen zou door verschillende factoren verklaard kunnen worden. Het is allereerst waarschijnlijk dat artsen doorheen de jaren steeds beter op de hoogte zijn geworden van de wettelijke meldingsverplichting. Daarnaast is de aanvaarding van euthanasie onder artsen ook gestegen, vermoedelijk onder andere door de vele debatten over euthanasie in de media en andere publieke fora. Artsen moeten niet langer geheimzinnig handelen en kunnen daardoor ook meer geneigd zijn om openheid van zaken te brengen. En tenslotte is gebleken dat het risico op vervolging dat melden met zich mee kan brengen zo goed als nihil is. De Commissie heeft sinds haar bestaan nog geen enkel geval van euthanasie doorgestuurd naar het Parket, wat artsen ook meer vertrouwen zal gegeven hebben in de meldingsprocedure.

Hoewel iets meer dan 50% van alle euthanasiegevallen in Vlaanderen gemeld werden, is dit toch vrij laag in vergelijking met Nederland waar het meldingspercentage in 2005 geschat werd op 80%. Er zijn een aantal zaken die dit verschil kunnen verklaren. Onze studie van gemelde en niet gemelde euthanasiegevallen op basis van de sterfgevallenstudie heeft aangetoond dat er in Vlaanderen veel meer 'onduidelijke' euthanasiegevallen voorkomen dan in Nederland waarbij er slechts een zeer gering levensverkortend effect is (vaak zelfs minder dan 24 uur) en de arts middelen gebruikt zoals morfine waarbij het levensverkortend effect zeer onzeker is. Deze gevallen worden door de arts zelf meestal niet als euthanasie beschouwd en bijgevolg ook niet gemeld. Bijkomend aan dat gegeven, is het zo dat Nederlandse artsen reeds veel langer ervaring hebben met melden van euthanasie en zich controleerbaar opstellen. Nederland kende, in tegenstelling tot België reeds decennia lang een gedoogbeleid ten aanzien van euthanasie en artsen werden al sinds het begin van de jaren tachtig door de KNMG gestimuleerd om open te zijn over hun levensbeëindigend handelen. In vergelijking met Nederlandse artsen is melden van euthanasie en medisch handelen laten controleren door een externe instantie voor Belgische artsen dus een relatief nieuw fenomeen. Naarmate zij hier meer kennis over en ervaring mee hebben, kan verwacht worden dat het meldingspercentage in Vlaanderen ook verder zal stijgen zoals dat in Nederland het geval was.

Een belangrijk hiaat in het onderzoek naar melding van euthanasie blijft Wallonië. Een meldingspercentage kon niet geschat worden voor dat deel van het land omdat recente overlijdenscertificaten daar niet beschikbaar zijn. Dat is een spijtige zaak omdat het lage aantal euthanasiemeldingen van Franstalige artsen aan de Commissie bij velen toch vragen oproept (20% Franstalige meldingen tegenover 80% Nederlandstalige meldingen). Hoewel een studie naar medische beslissingen aan het levenseinde in België vond dat euthanasie vaker voorkomt in Vlaanderen dan in Wallonië en in Wallonië continue diepe sedatie vaker voorkomt dan in Vlaanderen, waren deze verschillen in medische praktijk

niet significant en ook niet groot genoeg om de wanverhouding in het aantal meldingen tussen de twee landsdelen te kunnen verklaren. De studies beschreven in dit proefschrift bieden een aantal mogelijke bijkomende verklaringen. Ten eerste zou het kunnen dat Waalse artsen minder goed geïnformeerd zijn over de euthanasiewet en minder goed op de hoogte zijn van de meldingsverplichting dan Vlaamse artsen. In Vlaanderen is de media aandacht voor euthanasie immers groter en zijn er meer opleidingsinitiatieven voor artsen (bv. LEIF) aanwezig dan in Wallonië. Dit verschil in kennis kwam ook nog boven in de hypothetische casussenstudie, die aantoonde dat Waalse artsen minder vaak wisten dat de euthanasiecasus met spierverslappers moest gemeld worden dan Vlaamse artsen. Naast minder kennis bleek uit de attitudestudie ook dat Waalse artsen minder te vinden zijn voor maatschappelijke controle over euthanasie dan Vlaamse artsen en dat zij vaker vinden dat euthanasie een privézaak is tussen patiënt en arts waar de Commissie niet moet op toezien. Deze negatieve attitudes tegenover controle en tegenover de Commissie dragen naast een verschil in medische praktijk en een verschil in kennis ook bij tot het verklaren van de wanverhouding in het aantal meldingen door Nederlandstalige en Franstalige artsen.

Factoren die samenhangen met melden/niet melden van euthanasie

Uit onze studies is gebleken dat hoe een arts zijn of haar handeling benoemt van doorslaggevend belang is voor het al dan niet melden ervan. Handelingen die door de arts niet als euthanasie worden benoemt, worden door die arts ook niet gemeld. Dit bleek ook de vaakst genoemde reden te zijn die artsen gaven voor niet-melden: in 77% van alle niet-gemelde euthanasiegevallen in de sterfgevallenstudie zei de arts dat het geen geval van euthanasie betrof.
Het correct benoemend van euthanasie is vooral problematisch wanneer de euthanasie uitgevoerd wordt met opiaten of sedativa. Artsen die opiaten of sedativa toedienen met de bedoeling om het leven van de patiënt te beëindigen, zien deze handeling zelden als euthanasie. Dit bleek ook uit de casussenstudie: artsen benoemden de euthanasie uitgevoerd met opiaten veel minder vaak als euthanasie dan de klassieke euthanasiecasus met spierverslappers. De bereidheid van artsen om de casus met opiaten te melden was ook veel kleiner dan de bereidheid om de casus met spierverslappers te melden.

Naast het benoemen van de handeling zijn er nog enkele andere factoren die samenhangen met het al dan niet melden van euthanasie. Uit de hypothetische casussenstudie bleek dat de attitude van artsen tegenover euthanasie en tegenover maatschappelijke controle over euthanasie samenhangt met hun kennis van melding en hun bereidheid om zelf een hypothetische euthanasiecasus te melden. Artsen met een negatieve attitude waren minder op

de hoogte van de meldingsplicht en waren ook minder bereid om zelf te melden dan artsen met een positieve attitude. Dit zou te maken kunnen hebben met het feit dat artsen met een negatieve attitude minder geneigd zijn om zich te informeren over de euthanasiewet. Het omgekeerde is eventueel ook mogelijk: artsen die minder kennis hebben van de wet zullen een negatievere attitude hebben tegenover euthanasie of tegenover maatschappelijk controle.

Verder bleek dat geografische regio ook geassocieerd is met kennis over melding en meldingsbereidheid, zelfs na controle voor benoemen van de handeling en attitude tegenover euthanasie en tegenover maatschappelijke controle: Waalse artsen hebben minder kans om op de hoogte te zijn van de meldingsplicht en zijn minder bereid om zelf de euthanasiecasus te melden dan Vlaamse artsen. Dit kan dus niet enkel verklaard worden doordat Waalse artsen minder vaak euthanasiegevallen correct benoemen en een negatievere attitude hebben tegenover maatschappelijk controle. Zoals hierboven reeds aangehaald, zou dit dus ook te maken kunnen hebben met een verschil in geïnformeerd zijn tussen Waalse en Vlaamse artsen.
De grote regionale verschillen in melding van euthanasie zouden aangepakt kunnen worden met informatiecampagnes, specifiek gericht naar artsen in Wallonië.

Kenmerken van gemelde euthanasiegevallen

Op basis van een analyse van alle tussen 2002 en 2007 gemelde euthanasiegevallen konden we vaststellen dat in vergelijking met alle overlijdens in de populatie, patiënten die euthanasie verkrijgen vaker aan kanker lijden, jonger zijn, en vaker thuis overlijden.
Kanker heeft in vergelijking met andere ziekten een meer voorspelbare en duidelijkere prognose waardoor deze patiënten zich vaak beter bewust zijn van de terminale aard van hun ziekte. Hierdoor zouden ze sneller geneigd kunnen zijn om hun levenseinde samen met hun arts te plannen. Jongere patiënten zijn waarschijnlijk ook mondiger dan oudere patiënten om hun wensen omtrent hun levenseinde te uiten. Verder verkiezen patiënten waarschijnlijk om thuis te sterven in hun vertrouwde omgeving waar de euthanasie kan uitgevoerd worden door hun huisarts die ze vaak reeds jarenlang kennen. Omdat euthanasie op voorhand gepland kan worden, is thuis sterven voor deze patiënten ook goed te organiseren.

Vaak wordt in de internationale literatuur een vrees geuit dat zwakkere patiënten zoals ouderen vaker voor euthanasie zouden kiezen of gedwongen zouden worden hiervoor te kiezen. In onze studie vonden we geen aanwijzingen die deze vrees gronden. In tegendeel, ouderen boven 80 jaar

waren in vergelijking met hun aandeel in de algemene sterftepopulatie sterk ondervertegenwoordigd onder de gemelde euthanasiegevallen. Nu bleek het wel zo te zijn dat euthanasie bij ouderen minder vaak wordt gemeld dan bij jongere patiënten, hoogstwaarschijnlijk omdat bij deze patiëntengroep de euthanasie veel vaker met opiaten wordt uitgevoerd en daardoor door de arts niet als euthanasie beschouwd wordt. Indien we met dit gegeven rekening houden, dan nog zijn de 80-plussers nog steeds ondervertegenwoordigd onder de euthanasiegevallen, zelfs nadat gecontroleerd werd voor diagnose (ouderen hebben minder vaak kanker) en plaats van overlijden (rusthuizen hanteren vaker een restrictief beleid aangaande euthanasie). Bovendien stijgt hun aandeel onder de euthanasiegevallen ook niet doorheen de jaren. Hoewel de vrees met betrekking tot ouderen dus niet gegrond lijkt, kunnen we met de data van onze studies geen uitspraken doen over andere zogenaamde zwakkere patiëntengroepen zoals armen, laag opgeleiden, etnische minderheden, enzovoort.

Kenmerken van niet-gemelde euthanasiegevallen

Uit onze vergelijking van gemelde en niet- gemelde euthanasiegevallen werd duidelijk dat de meerderheid van de niet-gemelde euthanasiegevallen uitgevoerd werd met hoge dosissen opiaten en/of sedativa. Deze middelen worden in de medische literatuur sterk afgeraden voor euthanasie omdat ze een onzeker levensverkortend effect hebben en vervelende bijwerkingen kunnen hebben. In Nederland werden de meeste niet-gemelde euthanasiegevallen ook met opiaten uitgevoerd, maar het aantal zulke gevallen is daar veel lager dan in Vlaanderen. Dit verschil kan te maken hebben met het feit dat er in Nederland officiële richtlijnen bestaan voor zorgvuldige uitvoering van euthanasie, terwijl zulke richtlijnen niet bestaan in België. Ook de vereiste van medisch zorgvuldige uitvoering werd niet opgenomen in de Belgische wet zoals dat in de Nederlandse wel het geval is. De reden daarvoor was dat deze vereiste als overbodig werd beschouwd omdat een arts steeds medisch zorgvuldig dient te handelen. Bovendien is de Orde van Geneesheren van mening dat een arts autonoom moet kunnen beslissen over welke middelen hij of zij gebruikt om euthanasie uit te voeren. Het grote aantal euthanasiegevallen die werden uitgevoerd met opiaten wijst er echter op dat medisch zorgvuldige uitvoering van euthanasie helemaal niet zo evident is als gedacht en dat ook in België richtlijnen over de correcte uitvoering van euthanasie aangewezen zijn.

In een groot aantal van de niet-gemelde euthanasiegevallen werden de middelen bovendien toegediend door een verpleegkundige en niet door een arts zoals de wet voorschrijft. Dit werd ook al teruggevonden in een studie die werd uitgevoerd onder verpleegkundigen. Verpleegkundigen zijn vaak betrokken bij

het toedienen van opiaten in het kader van pijn- en symptoombestrijding. Het is goed mogelijk dat door de onduidelijke grens tussen euthanasie en pijn- en symptoombestrijding in deze situaties de verpleegkundigen het toedienen van opiaten voor euthanasie zien als louter een verlenging van de pijn- en symptoombestrijding die zij al aan het toepassen waren. Het moet echter opgemerkt worden dat de betrokkenheid van verpleegkundige bij de uitvoering van euthanasie wettelijk gezien problematisch is: verpleegkundigen die euthanatica toedienen riskeren zowel strafrechtelijke vervolging als disciplinaire maatregelen. Richtlijnen over de correcte uitvoering van euthanasie zouden niet enkel de grijze zone tussen euthanasie en pijn- en symptoombestrijding kunnen verkleinen door het gebruik van opiaten af te raden, maar tevens de betrokkenheid van verpleegkundigen in het uitvoeren van euthanasie verminderen.

Uit de vergelijking van gemelde en niet- gemelde euthanasiegevallen bleek tevens dat bij de niet-gemelde euthanasiegevallen het wettelijk verplichte op schrift gestelde verzoek vaak ontbrak waar dit bij gemelde gevallen zo goed als altijd aanwezig was. Het is mogelijk dat artsen dit op schrift stellen van het verzoek als overbodig zien omdat zij een vertrouwensrelatie hebben met de patiënt. Deze verklaring kwam naar boven in de interviewstudie met huisartsen. Het is ook mogelijk dat artsen niet voldoende op de hoogte zijn van deze wettelijke vereiste. Bovendien kan het zijn dat artsen, aangezien zij in de meeste niet-gemelde gevallen hun handeling niet als euthanasie beschouwen, zich er niet eens van bewust waren dat de wettelijke zorgvuldigheidsvoorwaarden voor euthanasie van toepassing waren.

Collega artsen en zorgverleners gespecialiseerd in palliatieve zorg werden significant minder vaak geconsulteerd in niet- gemelde dan in gemelde gevallen. Uit Nederlands onderzoek bleek ook reeds de sterke relatie tussen consultatie van een onafhankelijke tweede arts en melden van euthanasie: de belangrijkste reden die genoemd werd in dat onderzoek om geen tweede arts te consulteren was dat de arts niet van plan was de euthanasie te melden. Uit dat onderzoek bleek ook dat de beschikbaarheid van SCEN artsen die opgeleid zijn om expertadvies te geven en optreden als onafhankelijke tweede arts een positief effect had op het meldingspercentage. LEIF is een soortgelijk project in Vlaanderen ware het niet dat LEIF minder uitgebreid en ingeburgerd is als SCEN. Het verder ontwikkelen van het LEIF project zou een belangrijke rol kunnen spelen in het vergroten van de kennis die artsen hebben over de zorgvuldigheidsvoorwaarden en procedures voor euthanasie en zou in belangrijke mate kunnen bijdragen tot het verhogen van het meldingspercentage door het gemakkelijker beschikbaar maken expert artsen die als tweede arts kunnen fungeren bij euthanasieverzoeken.

Attitudes van artsen

Aanvaarding van euthanasie en het gebruik van levensbeëindigende middelen zonder verzoek van de patiënt

Negentig procent van de artsen in België die te maken kunnen hebben met zorg aan het levenseinde aanvaardt de praktijk van euthanasie voor patiënten met een terminale ziekte die extreme, oncontroleerbare pijn of ander lijden ervaren. Dit is een zeer hoge aanvaardingsgraad vooral gezien de beperkte steun voor legalisering van euthanasie onder artsen in andere landen. De aanvaarding van euthanasie door artsen in België is nog gestegen sinds de praktijk gelegaliseerd is; van 78% in 2002 naar 90% in 2009. De praktijk van euthanasie zelf is ook meer gangbaar geworden. De euthanasiewet, de wet betreffende de palliatieve zorg en wet inzake patiëntenrechten hebben mogelijks samen met de debatten die aan deze wetten vooraf gingen geleid tot een toegenomen bewustzijn van de rechten van terminaal zieke patiënten en tot een toegenomen steun voor zelfbeschikking van patiënten met betrekking tot medische beslissingen aan het levenseinde. Publieke debatten over euthanasie gaan vandaag niet langer over de vraag of de praktijk al dan niet aanvaardbaar is, maar over of de euthanasiewet al dan niet moet uitgebreid worden naar andere patiëntengroepen zoals minderjarigen en dementen. Euthanasie komt ook aan bod in opleidingen voor artsen, zowel op niveau van instellingen als op grotere schaal zoals de opleiding tot LEIFarts.
Hoewel de aanvaarding van euthanasie hoog is, is de bereidheid van artsen om zelf euthanasie uit te voeren lager. Dit is logisch aangezien het gemakkelijker is om een praktijk te steunen dan om er zelf verantwoordelijkheid voor te nemen.

Niet enkel euthanasie, maar ook het gebruik van levensbeëindigende middelen *zonder* verzoek bij terminaal zieke incompetente patiënten wordt in vrij hoge mate aanvaard door de artsen, hoewel die praktijk in België nog steeds illegaal is. Opvallend was dat artsen die meer ervaring hebben in zorg voor stervende patiënten een hogere kans hebben om levensbeëindiging zonder verzoek te aanvaarden dan minder ervaren artsen. Op het eerste zicht lijkt dit contradictorisch omdat juist van deze artsen mag verwacht worden dat zij goed op de hoogte zijn van de illegale status van deze handeling. Echter, net in hun ervaring met zorg voor stervende patiënten zou een mogelijke verklaring kunnen liggen. Door de constante en directe ervaring met menselijk lijden kan het zijn dat deze artsen het gebruik van levensbeëindigende middelen zonder verzoek bij incompetente patiënten als een verantwoorde keuze zien wanneer het lijden van deze patiënten op geen enkele andere manier meer kan verlicht worden. Deze verklaring wordt ondersteund door een studie uitgevoerd bij verpleegkundigen die vond dat verpleegkundigen die rechtstreeks instaan voor de zorg van patiënten een hogere aanvaarding kennen van levensbeëindiging

zonder verzoek dan hoofdverpleegkundigen of verpleegkundigen met een managementfunctie. Men zou verwachten dat dezelfde redenering opgaat voor artsen die opleiding gevolgd hebben in palliatieve zorg, maar onze studie toonde aan dat deze artsen net minder kans hebben om deze praktijk te steunen, vermoedelijk door de sterkte focus in palliatieve zorg op patiëntenautonomie.

De kans op aanvaarding van het gebruik van levensbeëindigende middelen zonder verzoek bij terminaal zieke incompetente patiënten was ook hoger bij artsen uit Brussel dan bij artsen uit Vlaanderen of Wallonië. Een studie over medische praktijken aan het levenseinde in Brussel vond ook al dat de incidentie van deze praktijk hoger is in Brussel dan in de andere delen van het land. In vergelijking met Vlaanderen, komen ziekenhuisoverlijdens veel vaker voor in Brussel. Geweten is ook dat het gebruik van levensbeëindingende middelen zonder verzoek vaker voorkomt in ziekenhuizen. In ziekenhuizen ligt ook vaak de klemtoon meer op genezing dan op comfortzorg, waardoor vroegtijdige zorgplanning aan het levenseinde vaak niet evident is. Hierdoor is de kans ook groter dat de wensen van de patiënt niet gekend zijn door de arts.

Maatschappelijke controle over de euthanasiepraktijk

De overgrote meerderheid van de onderzochte artsen onderschrijft de nood aan maatschappelijke controle over de euthanasiepraktijk. Desondanks vindt één op vier van de artsen dat euthanasie een privézaak is waar de Commissie niet op toe moet zien. Vooral artsen uit Wallonië en in mindere mate artsen uit Brussel zijn van deze mening.
Opvallend was dat religieuze artsen, en dan vooral sterk praktiserende Rooms-Katholieke artsen het vaker eens waren dat maatschappelijke controle noodzakelijk is dan niet-religieuze artsen. Auteurs hebben geargumenteerd dat sterke geloofsovertuigingen geassocieerd zijn met een zorgvuldige medische praktijk aan het levenseinde. Verder hebben ook verschillende studies uitgewezen dat de waarden van solidariteit met de gemeenschap en verantwoordelijkheid voor anderen sterker aanwezig zijn in sterk religieuze groepen dan in minder of niet-religieuze groepen. Dit zou mogelijk mee kunnen verklaren waarom sterk religieuze artsen een grotere kans hebben om de idee van maatschappelijke controle en verantwoording afleggen aan de samenleving te steunen.

Niet enkel sterk praktiserende Rooms- Katholieke artsen, maar ook artsen die een opleiding in palliatieve zorg gevolgd hebben, hadden een grotere kans om maatschappelijke controle over de euthanasiepraktijk noodzakelijk te vinden dan artsen die geen opleiding gevolgd hadden. Artsen die een opleiding gevolgd

hebben, zijn waarschijnlijk beter geïnformeerd over de verplichte meldingsprocedure en zijn daardoor misschien ook meer overtuigd van de nood om euthanasiegevallen te melden en zulke verreikende handelingen ter verantwoording aan de maatschappij openbaar te maken.

De relatie tussen euthanasie en palliatieve zorg

Euthanasie en palliatieve zorg worden vaak als antagonistisch beschouwd. De Ethics Taskforce van de European Association of Palliative Care heeft zelfs expliciet gesteld dat euthanasie geen deel uitmaakt van de verantwoordelijkheid van de palliatieve zorg. Dit standpunt wordt gedeeld door menig expert in palliatieve zorg. Sommigen hebben echter ook geargumenteerd dat de situatie in België anders is en dat euthanasie en palliatieve zorg niet antagonistisch zijn, maar veeleer elkaar aanvullen. Een model van palliatieve zorg dat ook de mogelijkheid van euthanasie inhoudt, wordt gesteund door de Federatie Palliatieve Zorg Vlaanderen. De opvatting dat euthanasie deel kan uitmaken van goede zorg aan het levenseinde wordt gesteund door de overgrote meerderheid van de artsen in België die te maken kunnen hebben met zorg aan het levenseinde; slechts 10% vindt dat de euthanasiewet de verdere uitbouw van de palliatieve zorg verhindert. Opvallend ook was dat artsen die een opleiding in palliatieve zorg gevolgd hadden geen negatievere attitude tegenover euthanasie hadden dan artsen die geen opleiding gevolgd hadden. Artsen met opleiding in palliatieve zorg zagen in feite in mindere mate een negatief effect van de euthanasiewet op de ontwikkeling van de palliatieve zorg en hadden meer kans om ooit zelf al euthanasie uitgevoerd te hebben dan andere artsen. Deze bevindingen liggen in de lijn van een andere studie die vond dat euthanasie in België vaak voorkomt in de context van multidisciplinaire levenseindezorg.
De integratie van euthanasie en palliatieve zorg werd ook teruggevonden in de studie over gemelde euthanasiegevallen waaruit bleek dat artsen in één op drie gemelde gevallen een palliatief team geconsulteerd hadden. Euthanasie en palliatieve zorg worden dus niet als incompatibel beschouwd door Belgische artsen, maar eerder als integrale aspecten van levenseindezorg.

Curriculum Vitae Tinne Smets

Tinne Smets was born on May 8, 1980 in Turnhout, Belgium. She studied Latin – Modern Languages in high school. At the Katholieke Universiteit Leuven, she obtained a Masters degree in Communication Sciences in 2002 and a Candidates degree in Law in 2003. She started working as a management assistant at a hospital, while studying as a work student at the Vrije Universiteit Brussel, where she followed several courses in Psychology. In 2006, she started working at the Vrije Universiteit Brussel as a researcher at the End-of-Life Care Research Group, Department of Medical Sociology, Faculty of Medicine and Pharmacy. There she conducted her PhD research as part of a larger research project funded by the Institute for the Promotion of Innovation by Science and Technology Flanders. Tinne is today still working as a researcher at the End-of-Life Care Research Group.

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