

Euthanasia practice in Belgium

A population-based evaluation of trends and currently debated issues

Sigrid Dierickx

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Sigrid Dierickx

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Promotors: Prof. dr. Kenneth Chambaere (Vrije Universiteit Brussel)
Prof. dr. Luc Deliens (Ghent University)

Co-promotor: Prof. dr. Joachim Cohen (Vrije Universiteit Brussel)

Examination Committee:

Chair: Prof. dr. Dirk Devroey (Vrije Universiteit Brussel)

Other members: Prof. dr. Mark De Ridder (Vrije Universiteit Brussel)
Prof. dr. Wim Distelmans (Vrije Universiteit Brussel)
Prof dr. An De Sutter (Ghent University)
Prof dr. Kurt Audenaert (Ghent University)
Prof dr. Suzanne van de Vathorst (Erasmus MC Rotterdam,
the Netherlands)
Prof dr. Johannes van Delden (UMC Utrecht, the
Netherlands)

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Chapters 3-9 are based on the following publications

Chapter 3

Dierickx S, Deliens L, Cohen J, Chambaere K. Euthanasia in Belgium: trends in reported cases between 2003 and 2013. *CMAJ*. 2016 Nov 1;188(16):E407-E414.

Chapter 4

Dierickx S, Deliens L, Cohen J, Chambaere K. Comparison of the expression and granting of requests for euthanasia in Belgium in 2007 vs 2013. *JAMA Intern Med*. 2015 Oct;175(10):1703-6.

Chapter 5

Dierickx S, Cohen J, Vander Stichele R, Deliens L, Chambaere K. Drugs used for euthanasia: a repeated population-based mortality follow-back study 1998-2013 (submitted)

Chapter 6

Dierickx S, Cohen J, Penders YWH, Onwuteake-Philipsen BD, Van der Heide A, Bosshard G, Puhan M, Ziegler S, Deliens L, Chambaere K. Commonalities and differences in legal euthanasia and legal assisted suicide in three countries: a population-level comparison (submitted)

Chapter 7

Dierickx S, Deliens L, Cohen J, Chambaere K. Involvement of palliative care in euthanasia practice in a context of legalized euthanasia: a population-based mortality follow-back study. *Palliat Med*. 2018 Jan;32(1):114-122.

Chapter 8

Dierickx S, Deliens L, Cohen J, Chambaere K. Euthanasia for people with psychiatric disorders or dementia in Belgium: analysis of officially reported cases. *BMC Psychiatry*. 2017 Jun 23;17(1):203.

Chapter 9

Cohen J, Dierickx S, Penders YWH, Deliens L, Chambaere K. How accurately is euthanasia reported on death certificates in a country with legal euthanasia: a population-based study. *Eur J Epidemiol*. 2018 Apr 21. [Epub ahead of print]

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PART I

INTRODUCTION

Chapter 1

Background, research questions and outline of this dissertation

1. Introduction

The dying experience and the way we deal with death and dying have changed considerably in Western society during the last century.¹ A century ago, death was primarily caused by infectious diseases, accidents and childbirth. Nowadays, sudden and unexpected deaths have become less common. Medical advances have contributed significantly to an increased life expectancy, and degenerative diseases such as cancer and cardiovascular diseases have become the leading causes of death.² The shift from infectious to degenerative diseases as main causes of death involves a lengthening of dying trajectories and an increasing number of people experiencing terminal illness before death. In this context, medical end-of-life decisions have become a substantial part of contemporary medicine.³

One possible decision that can be made at the end of life is the decision to perform euthanasia, which is the central subject of this dissertation. The term “euthanasia” (derived from the Greek “eu-thanatos”, literally meaning “good death”) is used to describe the practice in which the life of a person is intentionally ended, generally to relieve this person from further pain and suffering. Under certain circumstances, euthanasia may be a justifiable option at

the end of life. However, euthanasia remains a heavily ethically loaded issue, with ongoing debate in both permissive and non-permissive countries.

1.1. The “good death”: the option of euthanasia in a context of increased medicalization

Personal autonomy and the right to self-determination have become prominent in contemporary society. In the medical area, this resulted in increased attention for patient empowerment with the patient as an active participant in the medical decision-making process, including at the end of life.^{4,5} People should have the opportunity to make informed decisions about their own medical care and should be able to decide for themselves which treatment they want, when they do not want any more treatment, and in which circumstances they die. The passing of laws on patient rights in various countries can be seen as a result of this shift away from medical paternalism.⁶

Death and dying have increasingly been subjected to medicalization and fast-growing progress in medical technology in Western society.^{7,8} However, despite huge advances in the field of medicine over the last decades, death remains unavoidable. Moreover, the increased influence of medical-technological interventions may prolong life, but as a consequence it can also prolong suffering.

The medicalization of death and dying has been challenged by the medical-revivalist discourse.⁹ Within this patient-centered discourse, the idea that curative treatment is by definition beneficial is countered, and death is put forward as something familiar.^{9,10} As a consequence, in addition to prolonging life, quality of death and dying have become a focal point in end-of-life care.¹¹ The rise of the concept of ‘good death’, which is central to contemporary discourses in death and dying, illustrates this change in attitude. Recurring elements in the conceptualization of a good death include being in control, dying with dignity, having a sense of closure, dying at home in the presence of family and friends, and death free of pain.^{7,12–15}

The medical-revivalist death discourse is shared by both the ‘right to die movement’ and the ‘palliative care movement’, as both consider a good death in terms of autonomy, control, dignity, and acceptance.^{10,15,16} However, their statements of this good death differ, which results in different views towards the acceptance of euthanasia.¹⁰ For example, in the palliative care movement, control is exercised not over the exact timing of death, but over symptoms that

accompany the dying process through pain and symptom management. The right to die movement focuses on the autonomous patient's decision about how and when they choose to die and what constitutes unbearable suffering.

1.2. Distinguishing euthanasia and assisted suicide from other medical end-of-life decisions

In this dissertation, euthanasia is defined as the administration of drugs with the intention to end life at the explicit request of the patient. Conceptually akin to euthanasia is the practice of assisted suicide where a physician prescribes lethal drugs to a patient upon request to enable the patient to end his or her own life.

Before going further into detail on euthanasia and assisted suicide, it is important to clearly distinguish the practice from other decisions that potentially or certainly hasten death. These kinds of decisions are usually referred to as medical end-of-life decisions. A commonly used conceptual framework in studies on end-of-life decision-making is the one developed in the Netherlands and used for the first time in the Dutch nationwide study on end-of-life practices in 1990.¹⁷ The framework distinguishes end-of-life decisions by the nature of the act (e.g. withdrawing treatment or administering drugs), the intention of the physician (life-shortening taken into account as unintended effect or explicitly intended), patient involvement (explicit patient request or not), and the life-shortening effect.¹⁸ Box 1.1 provides an overview of the medical end-of-life decisions framework and definitions.

In addition to euthanasia and assisted suicide, a third type of physician-assisted death can be identified, i.e. the hastening of death without explicit patient request. This decision comprises the administration of drugs with the explicit intention of ending the patient's life, without the patient's explicit request.

In non-treatment decisions, the decision is made either to not initiate potentially life-prolonging treatment or to withdraw a treatment that has already been initiated.¹⁹ In some situations, it is thus acceptable for physicians to forgo treatments that may prolong life, such as aggressive treatments associated with the prospect of a low quality of life for the patient. These acts are also often referred to as "passive euthanasia".²⁰ Intensified alleviation of pain and symptoms concerns the administration of drugs for pain and/or symptom relief. Both non-treatment decisions and alleviation of pain and symptoms can be made

taking into account a possible life-shortening effect, or with a co-intention to hasten death.

Box 1.1 Medical end-of-life decisions framework and definitions

Non-treatment decision: The decision to withhold or withdraw potentially life-prolonging treatment, taking into account a possible life-shortening effect or with the explicit intention of hastening death.

Intensified alleviation of pain and other symptoms: This decision concerns the administration of drugs for pain and/or symptom relief taking into account a possible life-shortening effect or with a co-intention to hasten death.

Euthanasia: The administration of drugs by someone other than the patient with the explicit intention to end the patient's life, at the patient's explicit request.

Assisted suicide: The supply or prescription of drugs to be taken by the patient him/herself, with the explicit intention to enable the patient to end his or her life.

Hastening of death without explicit request from the patient: The administration of drugs with the explicit intention of ending the patient's life, without explicit request from the patient.

Continuous deep sedation until death: The administration of drugs to keep a patient in continuous deep sedation or coma until death.

Continuous deep sedation until death, also often termed “terminal sedation” or “palliative sedation” was not included in the original 1990 framework but was introduced in a subsequent study in 2001.²¹ Continuous deep sedation is an intervention of last resort for people with refractory symptoms. The practice is subject of strong debate, as some consider it a form of slow euthanasia, while others emphasize that it is to be distinguished clearly from euthanasia.^{22–25}

1.3. The euthanasia and assisted suicide debate: main arguments for and against medically assisted death

The call for legislation on euthanasia and assisted suicide has increasingly emerged globally. Even though the practice has been decriminalized in a number of countries, medically assisted death remains worldwide subject of intense medical, societal and academic debate. In the international debate several arguments are raised for and against legalisation, with a particular focus on a number of key concerns.

One of the main arguments in favour of euthanasia is based on the right of self-determination and the principle of autonomy.^{26,27} Proponents argue that individuals have the right to control their own body. Therefore, a person who is capable of decision-making should have the opportunity to determine when and how they die. Another important argument, based on the principle of beneficence, focuses on the physician's duty to alleviate pain and suffering.^{5,27} This argument states that intractable pain and suffering should be alleviated, and a possible way to do this may be euthanasia. In other words, assisting someone to die may be a preferable choice as further suffering of the patient can be avoided. In addition to the main arguments in favour of euthanasia based on the principles of autonomy and beneficence, other arguments include that having the option of euthanasia can provide psychological reassurance to patients as they can rely on having the option of euthanasia if needed, and that there is no substantive distinction between euthanasia and withdrawing life-sustaining medical interventions.²⁷⁻²⁹

One of the main objections being invoked against legalisation of euthanasia and assisted suicide is the so called *slippery slope* argument. According to this argument, a particular course of action will inevitably lead to undesirable and unintended consequences. In the context of assisted death this means that, if euthanasia and assisted suicide are legalized, this will lead to error, abuse, and the violation of the rights of vulnerable people such as the elderly, the disabled and people with psychiatric conditions.^{27,30-32} In other words, by allowing to end people's life upon request, ending people's life without request will increasingly occur. Also, opponents fear that ill or old people might feel pressured towards requesting euthanasia because they might see themselves as a burden for their family, or society in general.³³ A further argument against legalisation is that already available treatments, including palliative care, are sufficient to effectively relieve pain, making the option of euthanasia redundant. Other arguments against

allowing euthanasia include that it would lead to worse care for the dying, that euthanasia practice cannot be properly regulated, and that it severely weakens the patient-physician relationship.^{27-29,34}

This dissertation contributes to the debate by providing population-based evidence on trends in Belgian euthanasia practice and on specific issues regarding euthanasia that are currently subject of debate. But first, in the following paragraphs I will go further into detail on the Belgian euthanasia legislation, the international legal context regarding euthanasia and assisted suicide, and previously conducted empirical research on euthanasia.

2. The Belgian law on euthanasia

2.1. The process towards euthanasia legislation

The euthanasia legalisation process took off in Belgium during the 1980s with the founding of two ‘Right to Die Associations’ advocating the right to euthanasia, more specifically *Recht op Waardig Sterven* in Flanders and the *Association pour le Droit de Mourir dans la Dignité* in Wallonia. During the following 20 years, several euthanasia laws were proposed by Liberal and Social-Democrat members of Parliament.³⁵ None of these actually led to euthanasia legislation, mainly because of the strong opposition towards euthanasia of the Christian Democrats who were in power uninterruptedly from 1958 onwards.

Nevertheless, in 1997 the Federal Advisory Committee on Bioethics evaluated the desirability of legal regulation of euthanasia practice. The multidisciplinary and pluralistic Committee could not reach consensus and therefore came up with four proposals.³⁶ The first proposal suggested an amendment of the penal code making euthanasia no longer punishable. In the second proposal the existing restrictions in the penal code would be retained, but under certain conditions the physician performing euthanasia would be considered to act in a situation of emergency. In addition, this proposal included an *a posteriori* control procedure in which the physician would be obliged to report the euthanasia case to the judicial authorities. The third proposal advised to install formal procedures for all medical end-of-life decisions, including but not limited to euthanasia. This proposal also included in case of euthanasia *a priori* evaluation by a third person and *a posteriori* societal or judicial control. The fourth proposal suggested to

maintain the legal prohibition of euthanasia, and that other means than euthanasia must be considered to relieve suffering.

The 1999 elections were an important turning point as the Christian Democrats were no longer represented in government for the first time in 40 years. This presented the coalition of Liberals, Social Democrats and Greens with the opportunity to bring euthanasia legislation back on the political agenda. Meanwhile, euthanasia had also become subject of vigorous debate in the media and among healthcare professional organisations.³⁷ Additionally, a study of end-of-life decisions in Flanders had shown that the illegal status of euthanasia did not prevent physicians from practicing euthanasia.³⁸ The coalition parties came up with a bill that formed a compromise between the different proposals of the Advisory Committee on Bioethics. The bill was finally approved by the Senate in October 2001 and by the Chamber of Representatives in May 2002. The law eventually came into effect on 23 September 2002.

2.2. The euthanasia law

According to the Belgian law on euthanasia of May 28th, 2002, euthanasia is defined as the intentional termination of life by another person than the person concerned, at this latter person's request.^{39,40} The law requires that the person who performs euthanasia is a physician. The physician who performs euthanasia does not commit a criminal offence if the norms and procedures prescribed by the law have been followed.

2.2.1. Due care requirements

Several substantive requirements are specified in the 2002 law. First, the patient must be an adult or an emancipated minor who is legally competent and conscious at the moment the euthanasia request is expressed. Second, the request must be voluntary, well-considered, repeated and expressed without any external pressure. Third, the patient must be in a medically hopeless situation with constant and unbearable physical or psychological suffering that cannot be alleviated. This situation of intolerable suffering must be the consequence of a serious and incurable condition caused by an accident or illness. The latter implies that the presence of a severe medical condition is a strict prerequisite to be eligible for euthanasia.

Chapter 1

In addition to the substantive requirements, the law stipulates two procedural requirements which function as control mechanisms. The first is the requirement to consult a fellow physician, who is independent from the patient and the attending physician, about the serious and incurable nature of the patient's condition. The second physician must consult the patient's medical file, examine the patient, and ascertain that the patient's physical or psychological suffering is constant and unbearable and cannot be alleviated. In case the attending physician judges that the patient is not expected to die in the near future a third physician, who is a psychiatrist or a specialist in the patient's illness, must be consulted. In addition, a one month waiting period is required before the performance of euthanasia.

The second procedural requirement is the notification of the euthanasia case to the Federal Control and Evaluation Committee on Euthanasia (FCECE). After performing euthanasia, the attending physician is required to fill in a euthanasia registration form, which was developed by the FCECE. This form must be sent to the FCECE within four working days after performing euthanasia.

Assisted suicide is not mentioned in the Belgian Act on Euthanasia. An advice regarding euthanasia and other medical end-of-life decisions issued by the National Council of the College of Physicians in 2003 states that assisted suicide is equal to euthanasia, insofar all legal due care criteria for euthanasia are complied with.⁴¹ The FCECE also treats assisted suicide as a form of euthanasia.⁴²

The 2002 law was limited to adults and emancipated minors, as inclusion of euthanasia for minors would have threatened approval of the bill. However, in 2014 the euthanasia law was extended to include competent minors, making Belgium the first country worldwide to legalize euthanasia for minors without any age restriction.^{43,44} Additional requirements are in place in these cases. The patient must be terminally ill and in a state of unbearable physical suffering. Also, the child must possess "capacity of discernment", i.e. have the mental capacity to make life-and-death decisions. This should be assessed by a psychiatrist or psychologist specialised in child and youth therapy. The final decision whether or not to grant the request is made with approval of the child's parents or legal guardians. Further, the child's relatives must be offered the possibility of psychological support.

2.2.2. The Federal Control and Evaluation Committee on Euthanasia (FCECE)

To safeguard carefulness and legal compliance of the practice and to enable societal control and evaluation, physicians who perform euthanasia are required to report each case of euthanasia to the multidisciplinary FCECE. The FCECE reviews the reported cases and determines whether euthanasia was performed in accordance with the legal requirements. Initially, only anonymous information is reviewed; where there is doubt about legality, the FCECE can revoke anonymity by majority decision and can ask the reporting physician for additional information. If the FCECE is of the opinion, based on a two-thirds majority, that the legal requirements were not fulfilled, the case is sent to the public prosecutor. In 2015 the FCECE referred for the first (and up until now only) time a case to the public prosecutor. To facilitate societal control and transparency of the practice, the euthanasia law foresees in biannual evaluation of the law by the FCECE.

The FCECE is by law composed of 16 members. Eight members are physicians (of whom at least four are academic professors), four members are professors of law or lawyers, and four members are people with professional experience regarding people suffering from incurable illness. Three criteria of balance are taken into account for the composition of the FCECE: 1) language parity (the FCECE consists of eight Dutch-speaking and eight French-speaking members), 2) gender balance (at least three members of each gender), and 3) pluralistic representation (the FCECE is composed of members with different life stances).⁴⁵

2.2.3. The advance euthanasia directive

The euthanasia law also foresees in the possibility to draw up an advance directive in which one requests that euthanasia be performed should they be in an irreversible state of unconsciousness. The advance euthanasia directive must be recorded in writing and signed by two adult witnesses, of which one must not have any material interest regarding the patient's death. The advance euthanasia directive is valid for a maximum period of five years and must therefore be reconfirmed. Official registration of the advance euthanasia directive at the civil registry of the municipality is possible but not mandatory.

The advance euthanasia directive has two main limitations: 1) it only applies for people in a state of irreversible unconsciousness and thus not in case of loss of

mental capacity due to e.g. dementia, a reversible coma, loss of ability to communicate, etc. and 2) it only acts as a guide for the treating physician and is thus not a legally binding document, in contrast to the advance directive to refuse treatment.

2.3. The laws on palliative care and patient rights

Concurrently with the euthanasia law, the laws on palliative care and patient rights were enacted. The law on palliative care states that every patient has the right to access palliative care and determines measures for the further development of palliative care services.⁴⁶ The law on patient rights established the rights of patients to be informed and to consent to medical treatments.⁴⁷ The law specifies the right to refuse treatment, which can be documented in a legally binding advance directive or 'living will'. Further, the law also states the possibility to appoint a surrogate decision-maker to advocate for one's rights in case they become unable to make decisions or speak for themselves.

2.4. Implementation of the euthanasia law

The euthanasia legislation was not accompanied by a thorough plan for implementation of the law. Also, in contrast to the Netherlands, no relevant jurisprudence was available to guide the formulation of safeguards or implementation plans. This meant that when the law came into force, little was known about how the legal regulation could be translated into medical practice and care for people requesting euthanasia.⁴⁸

2.4.1. Consultation and training initiatives for euthanasia and other medical end-of-life decisions

When the euthanasia law came into effect, physicians still experienced a great deal of uncertainty regarding handling euthanasia requests and it was not always easy to find physicians willing to act as the legally required second (and sometimes third) physician. In response, some individuals active in palliative care together with the right to die association *Recht op Waardig Sterven* founded the Life's End Information Forum (LEIF) in 2003 in Flanders and Brussels.^{49,50} LEIF was based on the Support and Consultation in Euthanasia Networks (SCEN) in the Netherlands, which provides trained physicians to act as mandatory second

physicians during euthanasia procedures.^{51,52} The objectives of LEIF are however broader than SCEN's and go beyond merely offering support for physicians in the euthanasia procedure. LEIF provides training for physicians and nurses with the objective of increasing knowledge regarding end-of-life decision-making and palliative care.^{50,53} A service similar to LEIF, Forum End of Life, was established in Wallonia in 2003 but is more limited.

2.4.2. Development of euthanasia policies and guidelines

In the Netherlands, a guideline on the performance of euthanasia and assisted suicide was issued by the Royal Dutch Medical Association.⁵⁴ This guideline was available even before euthanasia and assisted suicide were formally legalized. The Belgian Medical Association issued a formal advice regarding the impact of the palliative care and euthanasia legislation on physicians' medical deontology⁴¹, but it did not provide Belgian physicians with a practice guideline for careful performance of euthanasia. Other health professional organisations, including LEIF, drew up guidelines for handling euthanasia requests and performing euthanasia, including the medical-technical aspects of euthanasia such as the drugs and equipment to be used.^{55,56} Care institutions developed ethics policies with guidelines on how to handle euthanasia requests within their institutions.⁴⁸ These policies are often more restrictive than the euthanasia law, for example by only allowing euthanasia for terminally ill patients.^{48,57,58}

3. The international context: countries with legislation allowing euthanasia or assisted suicide

Legalization of assisted death is subject of debate in several countries. Nevertheless, the practice is regulated only in a number of countries. Euthanasia and assisted suicide are legal in Belgium, the Netherlands, Luxemburg, Colombia, Canada, and as of mid 2019 in the Australian state of Victoria.^{59,60} Assisted suicide, excluding euthanasia, is possible in Switzerland and in parts of the United States, namely in seven states (Oregon, Washington, Vermont, Montana, California, Colorado and Hawaii) and Washington D.C. The most recent figures

on frequencies of euthanasia and/or assisted suicide in these jurisdictions as reported by their respective review instances are presented in Table 1.1.

3.1. The Netherlands

The Netherlands adopted the *Law on Termination of Life on Request and Assisted Suicide* in April 2002. In contrast to the situation in Belgium, by the time the Dutch law was voted the Netherlands had about 30 years of experience with the practice and in 1990 a formal and uniform notification procedure had already been developed and implemented.^{40,61} While the Belgian law explicitly mentions only euthanasia, the Dutch law includes both euthanasia and assisted suicide.

Several due care requirements are specified in the Dutch law which are largely similar to the Belgian requirements. Physicians must be satisfied that the patient's request is voluntary and well-considered, must have informed the patient about the patient's situation and prognosis, must have come to the conclusion – together with the patient – that there is no reasonable alternative in the patient's situation, and must have exercised due medical care and attention in terminating the patient's life or assisting in their suicide. Furthermore, physicians are required to report the euthanasia or assisted suicide case to one of five regional Euthanasia Review Committees, which check whether all due care criteria were adhered to. In 2016, 6091 cases were reported to the Dutch Committees, approximately 4% of all deaths in that year.⁶²

3.2. Luxembourg

The Luxembourg euthanasia law came into effect in 2009. It is largely based on the Belgian law, imposing the same substantive and due care requirements, however it explicitly includes physician-assisted suicide.⁶³ As was the case in Belgium, the Luxembourg law was accompanied by legislation on palliative care. The law also had constitutional implications as the Luxembourg Grand Duke's power was reduced to a largely ceremonial role, because he refused to sign the bill into law. The practice remains limited, with 10 cases reported to the National Commission for Control and Evaluation in 2016.⁶⁴

Table 1.1 Jurisdictions with euthanasia and/or assisted suicide legislation and frequency of reported euthanasia and assisted suicide

Jurisdiction	Year of legislation or landmark (in case of no specific legislation)	Euthanasia current status	Assisted suicide current status	Required diagnosis	Year of latest known number of deaths by euthanasia and/or assisted suicide	Number of deaths by euthanasia and/or assisted suicide ^a	Percentage of all deaths ^a
Switzerland	1942	Illegal	Legal	None	2014	742 ^c	1.2
Northern Territory (Australia)	1996 (overturned in 1997)	Legal	Legal	Terminal	1996-1997	7	b
Oregon (US)	1997	Illegal	Legal	Terminal, <6 months	2017	143	0.4
Netherlands	2002	Legal	Legal	None	2016	6091	4.1
Belgium	2002	Legal	Legal	Adults: none Minors: terminal	2015	2022	1.8
Luxembourg	2009	Legal	Legal	None	2016	10	b
Washington (US)	2009	Illegal	Legal	Terminal, <6 months	2016	192	b
Montana (US)	2009	Illegal	Legal	None specified	b	b	b
Vermont (US)	2013	Illegal	Legal	Terminal, <6 months	b	b	b
California (US)	2015	Illegal	Legal	Terminal, <6 months	2016	111	0.06
Colombia	2015	Legal	Legal	Terminal	b	b	b
Colorado (US)	2016	Illegal	Legal	Terminal, <6 months	2017	56	b
Canada	2016	Legal	Legal	Terminal	2017	1179 ^c	b
District of Columbia (US)	2016	Illegal	Legal	Terminal, <6 months	b	b	b
Victoria (Australia)	2018	Legal	Legal	Terminal	b	b	b
Hawaii (US)	2018	Illegal	Legal	Terminal, < 6months	b	b	b

^aThese figures represent the euthanasia and assisted suicide practice as reported to the countries' respective review instances or statistical offices. Numbers and percentages may therefore differ from euthanasia and assisted suicide practice as estimated through population-based surveys.

^bData not (yet) available.

^cThis is the number of assisted suicides involving Swiss residents. The Swiss Federal Statistics Office does not know the number of cases of assisted suicide involving persons not resident in Switzerland.

^dEven though assisted suicide is not mentioned in the Belgian Act on Euthanasia, it is treated as a form of euthanasia by the Belgian euthanasia review committee provided that all legal due care criteria for euthanasia are complied with.

^eNumber of medically assisted deaths in Canada between January 1 and June 30, 2017.

3.3. Switzerland

In accordance with article 115 of the Swiss Penal Code of 1918, assisted suicide is permitted on the condition that the person assisting does so without any “selfish motives”, in other words in the absence of any self-interest (such as monetary gain).⁶⁵ Physician-assisted suicide was therefore not explicitly legalized, but it is considered to be legal under Article 115. In contrast, euthanasia is not permitted; the law only allows providing means to commit suicide.

Since there is no specific legislation on assisted suicide, there are no legal provisions on how the practice should be carried out. Assisted suicide is thus not restricted to people with a terminal illness or to Swiss residents, additionally it does not require involvement of a physician in assisting a person to die.^{60,66,67} The role of physicians is limited to assessing whether the person requesting assisted suicide has decision-making capacity and to prescribing the lethal drugs. Swiss non-profit right to die associations, of which Dignitas and Exit Deutsche Schweiz are the two largest ones, were first established in the 1980s.⁶⁸ Volunteers working for these association have since then been assisting people with suicide by providing them with life-ending drugs. As assisted suicide is not restricted to Swiss residents, the phenomenon of “suicide tourism” developed, with people from non-permissive countries travelling to Switzerland with the purpose of seeking assistance in dying.⁶⁹

The Swiss Federal Statistics Office, which is the instance responsible for Swiss death certificates, reports that in 2014, 742 cases of assisted suicide were registered in Switzerland, which corresponds to 1.2% of all deaths that year.⁷⁰ This number only includes persons who are Swiss residents.

3.4. The United States

Assisted suicide is legally possible for terminally ill and mentally competent adults in seven federal states in the United States and in Washington DC.^{59,71} Six states, i.e. Oregon, Washington, Vermont, California, Colorado and Hawaii, and Washington DC legalized assisted suicide through legislation. One state, i.e. Montana, has legal assisted-suicide through court ruling. In contrast to the Belgian and Dutch assisted dying practice, euthanasia is not allowed and the presence of a physician when the lethal drugs are administered is not required.

In 1997 Oregon became the first state to legalize assisted suicide for terminally ill, mentally competent adults. The *Oregon Death With Dignity Act* allows terminally

ill adults with less than six months to live to end their lives through the voluntary self-administration of a lethal dose of medication prescribed by a physician. The most recent report of the Oregon Public Health Division shows that in 2017, 218 people received prescriptions to access lethal doses of medication and 143 people died from ingesting the prescribed medications.⁷² In 2008 Washington followed with its own *Death With Dignity Act*. The latest report from Washington mentions that medication was prescribed to 248 people in 2016, of which 192 died after ingesting the medication.⁷³ In Montana, aid in dying became legal through a state Supreme Court decision in 2009. State law allows for terminally ill people to request lethal drugs from a physician under existing statutes. No figures are available for assisted suicide practice in Montana. In 2013 legislature in Vermont passed the *Patient Choice and Control at End of Life Act*, which is based on the Oregon model. Physicians are required to report to the Vermont Health Department, but figures are not available. In 2015 assisted death was legalized in California with the *End of Life Option Act*. The California Department of Public Health reports that in 2016, 191 people received prescriptions for lethal drugs under the Act whilst 111 people actually died from ingesting the prescribed drugs.⁷⁴ In 2016 the Colorado *End of Life Options Act* was voted. The Colorado annual statistical report for 2017 shows that 56 people died following prescription of aid-in-dying medication.⁷⁵ In the American state of Hawaii assisted suicide legislation will take effect in January 2019 after the *Our Care, Our Choice Act* was passed in April 2018.

3.5. Canada

In 2014, the Canadian province of Quebec passed the *Act Respecting End-of-Life Care*, making euthanasia, in Canada most often referred to as ‘Medical Assistance in Dying’ or ‘MAiD’ available for competent adults from Quebec with a serious and incurable illness.⁵⁹ As a result of the ruling of the Supreme Court of Canada in the Carter versus Canada case in 2015, assisted suicide and euthanasia became legal in the whole of Canada.⁷⁶ The Court ruled that, in order to follow the Canadian Charter of Rights and Freedoms, the part in the Canadian Criminal Code prohibiting medical assistance in dying would need to be changed. The Supreme Court gave the government until June 6, 2016 to create a new law. Eventually in 2016 Canada’s parliament passed the federal Bill C-14 legalizing and regulating assisted dying. The *Medical Assistance in Dying Law* applies to mentally capable adults who suffer from a grievous and irremediable medical condition and who make a voluntary request for medical assistance in dying. One

must experience unbearable physical or mental suffering as a result of illness, disease or disability. Additionally, natural death should have become reasonably foreseeable. The 2nd Interim Report of Health Canada mentions 1179 medically assisted deaths between January 1, 2017 and June 30, 2017. These account for approximately 0.9% of all deaths in Canada during that time frame.

3.6. Colombia

In 2015, Colombia became the only Latin American country where euthanasia is legally possible. The Colombian Constitutional Court ruled in favour of euthanasia in 1997, but it was not until 2015 that the Ministry of Health specified how this could occur with strict safeguards.⁵⁹ Only adults suffering from terminal disease causing severe pain and suffering that cannot be relieved are eligible for euthanasia. Additionally, authorization of the patient's request is needed from a medical specialist, a lawyer, and a psychiatrist or clinical psychologist.

3.7. Australia

Euthanasia was briefly possible in Australia's Northern Territory as of 1996 through the *Rights of the Terminally Ill Act* of 1995.^{77,78} The Act regulated euthanasia and assisted suicide for terminally ill people, but was repealed by the Commonwealth Parliament in 1997 with the *Euthanasia Laws Act*. During the nine months that the law was active, seven people made use of the Act.⁷⁸ More recently, in February 2018, the Australian province of Victoria legalised euthanasia for terminally ill people over the age of 18 who are capable of making decisions.⁷⁹ The law will come into force as of mid 2019.

4. Empirical research on euthanasia

4.1. Euthanasia practice as estimated through nationwide surveys

Euthanasia prevalence has already been extensively studied, even in countries without euthanasia legislation and before euthanasia became legal in certain countries. The EURELD study conducted in 2001-2002 in six European

countries (Belgium, Denmark, Italy, the Netherlands, Sweden, and Switzerland) showed that euthanasia prevalence in these countries ranged from 0% (Sweden) to 2.8% (the Netherlands).³ More recent studies found that euthanasia prevalence has been increasing continuously in Belgium (from 1.1% in 1998 to 4.6% in 2013) and the Netherlands (from 1.7% in 1990 to 4.5% in 2015).^{80,81} Assisted suicide is relatively uncommon in both countries, with a prevalence of 0.1% both in Belgium and the Netherlands. In the German-speaking part of Switzerland, euthanasia prevalence remained stable (0.2% in 2001 vs 0.3% in 2013) but prevalence of assisted suicide increased from 0.3% in 2001 to 1.1% in 2013.⁸²

A study conducted in 2009 among a representative sample of 3006 Belgian physicians showed that 39% had received a euthanasia request since the introduction of euthanasia legislation.⁸³ About half of the requests expressed in the 12 month period before the study were carried out, 5% was refused, 10% had been withdrawn by the patient, and in 23% the patient had died before euthanasia could be performed. In a Dutch study conducted between 2000 and 2002 using the same method 78% of physicians had ever received a request for euthanasia. Of all requests expressed in the 12 months before the survey, 44% were granted, 12% was refused, 13% had been withdrawn by the patient, and 13% the patient had died before the performance.⁸⁴

4.2. Attitudes towards euthanasia of the general public and physicians

4.2.1. Public attitudes towards euthanasia

Public attitudes towards euthanasia differ substantially between countries. Over the last three decades support for euthanasia increased in most Western European countries.⁸⁵⁻⁸⁷ At the same time, acceptance of euthanasia and assisted suicide remained stable or even decreased in most Central and Eastern European countries.^{86,87} In Belgium, public acceptance of euthanasia has increased significantly between 1981 and 2008 but decreased slightly in the Netherlands since legalisation of euthanasia in 2002.⁸⁷ A study conducted in 2008 among 47 European countries found a fairly high public acceptance in a small number of Western European countries, including the three countries that have legalized euthanasia (the Netherlands, Belgium and Luxembourg) and France, Spain, Sweden and Denmark.⁸⁶ Elsewhere in Europe, public acceptance was shown to be moderate to low. Outside of Europe, an increase was found in euthanasia acceptance between 1977 and 2004 among the American public.^{88,89}

Several factors have been shown to influence people's stance on euthanasia, such as religious beliefs (people who consider themselves as belonging to no religious group are most accepting towards euthanasia), age (older age groups report lower euthanasia acceptance) and education (euthanasia acceptance is lower among the less educated).^{71,86,89-91}

4.2.2. Physicians' attitudes towards euthanasia

Physician support for euthanasia is relatively high in Belgium and the Netherlands. A cross-national study conducted in 2002 among physicians in six European countries and Australia showed that Dutch and Belgian physicians ranked highest for support for euthanasia for terminally ill people (respectively 77% and 78%).⁹² A study among Belgian physicians from 2009 found that a majority of physicians agree with euthanasia for terminally ill people (90%) and that euthanasia can be considered as part of good end-of-life care (75%).⁹³ Furthermore, in Belgium 81% of physicians (2009) and in the Netherlands 86% of physicians (2012) are prepared to perform euthanasia themselves.^{93,94}

Outside of Belgium and the Netherlands, physician support for euthanasia is considerably lower. In the United States for instance, less than half of physicians support legalization of euthanasia and assisted suicide.⁹⁵⁻⁹⁸ Most of these studies date however from before introduction of assisted suicide legislation in the US; more recent research on physician attitudes in the United States is not available. A systematic review of studies conducted between 1990 and 2010 among UK physicians concluded that the majority of UK physicians oppose legalization of euthanasia and assisted suicide.⁹⁹

Similar to public attitudes, religious beliefs have been shown to be an important factor influencing physicians' stance towards euthanasia.^{92,93,99,100} With specific regard to Belgium, geographic region strongly determines physicians' attitudes, with Walloon physicians being more negative towards performing euthanasia and the reporting obligation compared to Flemish physicians.^{93,101}

5. Objectives and research questions

This dissertation has two main objectives, each consisting of several research questions. The first objective is to examine trends in euthanasia practice. The second objective is to inform current debates regarding euthanasia.

5.1. Objective 1: to examine trends in euthanasia practice

Concerns about developments in end-of-life and euthanasia practice in Belgium persist, particularly abroad. More specifically, concerns are regularly voiced regarding the slippery slope and possible abuse, especially with regard to patient groups that are considered vulnerable, such as older people and people suffering from psychiatric diseases. Therefore, the frequency of euthanasia, the socio-demographic patterns in its application and the characteristics of the decision-making process need to be monitored. Trends and developments in end-of-life practices, including euthanasia, provide insight into evolutions in the quality of end-of-life practices. Additionally, studying trends allows identification of priorities for medical practice at the end of life.

In their biannual report, the FCECE provides basic statistics on the reported euthanasia practice, but a detailed insight into long-term trends is lacking. Also, in addition to data on the reported euthanasia practice, repeated population-based surveys are needed in order to contribute to a more complete understanding of the practice.

To address the first objective, the following research questions are studied in this dissertation:

- 1 Which trends have occurred in officially reported euthanasia cases with regard to patient's sociodemographic and clinical profiles, as well as decision-making and performance characteristics?
- 2 Which trends have occurred in the expression and granting of euthanasia requests and the reasons that physicians granted or denied these requests?
- 3 What are the changes over time in drugs used to perform euthanasia and what are the differences in case characteristics according to the drugs used?
- 4 What are the differences and commonalities in euthanasia and assisted suicide practice in Belgium, the Netherlands and Switzerland?

5.2. Objective 2: to inform current debates regarding euthanasia

Empirical evidence on the euthanasia practice in countries where it is legal is needed to inform current euthanasia debates. Additionally, the option of medical assistance in dying is being discussed in an increasing number of jurisdictions.¹⁰² Experience in countries that have already adopted euthanasia legislation can help inform the ongoing international euthanasia debate. In this dissertation, I will focus on three particular issues in the euthanasia debate, i.e. the relation between euthanasia and palliative care, euthanasia for people suffering from psychiatric disease or dementia, and registration of euthanasia on the death certificate.

5.2.1. Euthanasia and palliative care

In essence, euthanasia and palliative care share many medical and ethical values such as an emphasis on patient autonomy, the importance of alleviating suffering, and the pursuit of a ‘good death’.¹⁰³ However, a recurrent discourse in the international debate about assisted dying is that euthanasia is incompatible with good palliative care. Frequently used arguments are that palliative care cannot intend to hasten death, and that providing euthanasia within a palliative care context endangers trust in physicians and causes distress in health care professionals, patients and relatives.^{104–107} Another concern is that allowing euthanasia might impede development of palliative care.^{33,106}

In Belgium, the palliative care movement and advocacy for euthanasia legislation developed side by side, culminating in a parallel legislation on both euthanasia and palliative care in 2002.^{108,109} This resulted in what has been named the Belgian model of integral end-of-life care, which includes euthanasia as an option at the end of a palliative care pathway.^{109,110} Additionally, the Flemish Federation for Palliative Care was the first palliative care organisation worldwide endorsing the viewpoint that euthanasia can be embedded in palliative care.¹¹¹ This rather unique context makes it highly relevant to study the involvement of palliative care services in euthanasia practice. This leads us to the following research question:

- 5 To what extent are palliative care services involved in the care of people requesting euthanasia, and in the decision-making and performance of euthanasia?

5.2.2. Euthanasia for people suffering from psychiatric disease or dementia

Belgium is one of the few countries where physicians can legally grant requests for euthanasia on the basis of unbearable suffering caused by psychiatric illness or dementia. The option of euthanasia for persons with psychiatric illness and dementia gives rise to concerns regarding the assessment of the legal criteria.¹¹²⁻

¹¹⁴ Firstly, legal competence of these patients is complex to assess, as the patient's capacity to make decisions in a competent manner may be impaired. Secondly, the patient's suffering being unbearable is crucial in the assessment of a euthanasia request. The term 'unbearable' has however been criticized for being too vague, especially in regard to psychological suffering. Thirdly, specifically with regard to psychiatric disorders, questions are raised as to whether such illness can be considered to be incurable and without prospect of improvement, as these illnesses tend to fluctuate in severity over time.

Euthanasia for psychiatric illness sparks intense societal debate, with both heavy opponents and strong contestants appearing regularly in popular media. Proponents, among whom many academics and physicians, argue that euthanasia should be available to people with unbearable and hopeless mental suffering due to psychiatric disorders, even in the absence of a somatic disease.¹¹⁵ Among contestants are many psychiatrists and psychologists, asking for a thorough evaluation of the euthanasia law, a reform of the FCECE and *a priori* review of euthanasia request for mental suffering.¹¹⁶ In March 2017, the Belgian Brothers of Charity Group decided to allow euthanasia in non-terminally ill people experiencing unbearable mental suffering within their institutions.¹¹⁷ Despite the fact that this view was criticized by the Catholic Church – even with accompanying threats to exclude the Belgian Group from Church – the Brothers of Charity stuck to their decision.¹¹⁸ Popular media have also been reporting on several high-profile cases involving people with psychiatric disorders and dementia.¹¹⁹⁻¹²²

Little is known about the prevalence and characteristics of euthanasia for psychiatric disorders and dementia in Belgium apart from casuistry. People with psychiatric disorders or dementia are often considered to be a vulnerable population. Taking into account slippery slope fears and the complexity of assessment of euthanasia requests expressed by persons with a psychiatric disorder or dementia, monitoring the euthanasia practice for these persons is most important. A thorough examination of the practice as reported by physicians is thus needed. We examine the following research question:

- 6 How has the prevalence and number of reported euthanasia cases with a psychiatric disorder or dementia diagnosis changed in Belgium and what are the demographic, clinical and decision-making characteristics of these cases?

5.2.3. Registration of euthanasia on death certificates

Concerns frequently arise regarding the manner in which euthanasia is being registered in countries where it is legal. Jurisdictions with legal euthanasia are faced with the question whether euthanasia should be recorded on the death certificate, and if so, in what manner.¹²³ In Belgium, the euthanasia law determines that death by euthanasia, insofar all legal regulations are adhered to, is to be indicated as a natural death on the death certificate.^{39,124} Additionally, euthanasia can be certified as the immediate cause of death on the death certificate. However, by registering euthanasia on the death certificate, the physician who performed euthanasia does not remain anonymous. Also, the patient might not want anyone to know he or she died by euthanasia.

Registration through death certificates has the potential to be a practical tool in monitoring euthanasia. However, little is currently known about how frequently euthanasia is recorded on the death certificate. We will address the following research question:

- 7 How accurately is euthanasia reported on death certificates?

6. Outline of this dissertation

Part I started with a general introduction and outlined the objectives of this dissertation. Following this general introduction, Chapter 2 deals with research methods used to examine the research questions above. Chapters 3-9 are based on scientific articles that have been published, accepted or submitted for publication.

Part II addresses objective 1 and is concerned with trends in euthanasia practice. Chapter 3 examines trends in reported euthanasia cases in Belgium between 2003 and 2013. Chapter 4 describes trends in the expression and granting of euthanasia requests in Flanders, Belgium in 2007 vs 2013. Chapter 5 provides insight into trends in drugs used to perform euthanasia in Flanders between 1998, 2007 and

2013. Chapter 6 compares euthanasia and assisted suicide practice in Belgium (Flanders), the Netherlands and Switzerland.

Part III addresses objective 2 and deals with three specific issues in the current euthanasia debate. Chapter 7 studies the involvement of palliative care services and professionals in euthanasia practice in Flanders. Chapter 8 is concerned with euthanasia for people suffering from psychiatric disease or dementia in Belgium. Chapter 9 describes the accuracy of euthanasia reporting on death certificates in Flanders.

Part IV presents a general discussion of the main findings of this dissertation, reflections on the strengths and limitations of the used study methods and implications of the findings and recommendations for policy, practice and future research.

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Chapter 2

Methods used in this dissertation

1. Introduction

This chapter describes the methods that were used to address the research questions of this dissertation. These research methods have in common that they are quantitative in nature and study euthanasia practice through retrospective data collection on population-level. Two chapters (Chapters 3 and 8) use administrative data routinely collected by the Belgian Federal Control and Evaluation Committee for Euthanasia. Five chapters (Chapters 4, 5, 6, 7 and 9) use population-based survey data from physicians attending a representative sample of deaths in Flanders.

2. Analysis of the data collected from the euthanasia cases reported to the Belgian Federal Control and Evaluation Committee for Euthanasia

2.1. Study design

As specified in the Belgian Law on Euthanasia, all cases of euthanasia must be reported to the Federal Control and Evaluation Committee for review.^{7,8} We

studied all 8,752 cases of euthanasia reported by physicians in Belgium to the Committee between implementation of the euthanasia law on September 22, 2002 and December 31, 2013. Data were collected by the Federal Control and Evaluation Committee for Euthanasia from the official standardized euthanasia registration forms submitted by the reporting physicians. The Belgian euthanasia law allows for these data to be made available, on an anonymous basis, for academic research purposes, upon reasonable request to the Committee.⁷

2.2. Data collection

Data are collected by the Committee for evaluation and control purposes through the use of a standardized registration form.^{7,8} The registration form was developed by the Committee and consists of two parts. The first part is confidential and includes the identity of the patient, the attending physician and the consulted physician(s). The Committee may not use this document for evaluation but may decide by majority vote to revoke the anonymity and contact the physician for further information in case of irregularities. This information is not included in the anonymized database we received. The second part contains specifications about age, sex and diagnosis of the person receiving euthanasia, the type of and reasons for the request, place and date of death, and the euthanasia procedure followed. On the basis of this part the Committee determines whether the performance of euthanasia was in accordance with the conditions and procedures stipulated by law. The registration form contains both open-ended and closed questions with pre-structured response categories.

2.3. Analysis

In the database we received, the open-ended questions had been encoded into categories by the committee. We checked the data for coding quality and, if necessary, recoded to obtain consistency over the years in coding of variables. Inconsistencies in the data were checked and clarified with the committee.

2.4. Ethics approval

The study protocol was approved by the Ethical Review Board of the University Hospital of the Vrije Universiteit Brussel.

3. Mortality follow-back survey using a representative sample of death certificates

3.1. Study design

A post-mortem survey on end-of-life decisions using a representative sample of death certificates (N=6,871) was undertaken in Flanders, Belgium in 2013. This study design has been repeatedly applied and validated to evaluate end-of-life care and decision-making.¹⁻⁴ The survey is a replica of 3 previous large-scale nationwide studies held in Flanders in 1998, 2001 and 2007.

The survey is based on a large and representative sample of death in Flanders, the semi-autonomous northern half of Belgium with approximately six million inhabitants and 58,000 deaths annually. A stratified random sample of deaths of Belgian residents aged one year or older from January 1st until June 30th, 2013 was drawn weekly at the Flemish Agency for Care and Health, the central administration authority for processing death certificates. All deaths were assigned to one of three strata, based on the cause of death as indicated on the death certificate and the estimated corresponding likelihood of an end-of-life decision. Sampling fractions for each stratum increased with this likelihood. In the first stratum, all deaths for which euthanasia was mentioned on the death certificate were sampled. In the second stratum, one third of all cancer deaths were sampled. In the third stratum, one in six deaths resulting from any other cause was sampled. This resulted in a sample of 6,871 deaths, about 21% of all deaths in the studied period. The sample size in 1998 was 3,999 deaths⁵, in 2001 it was 5,005 deaths⁴, and in 2007 it was 6,927 deaths⁶.

3.2. Data collection

Within two months of the death, certifying physicians received a four-page questionnaire with an introductory letter containing patient identifiers. Physicians were requested to complete the questionnaire by consulting the patient's medical file. If the certifying physician was not the treating physician, the certifying physician was instructed to pass on the questionnaire to the treating physician and to alert the researchers to this fact. One physician could receive participation requests for up to five decedents, with at most three reminders per death case. Returning the questionnaire was regarded as implicit consent of the physician to

participate in the study. After data collection a one-page questionnaire was mailed to all non-responding physicians inquiring about reasons for not participating. The response rate was 60.6% in 2013 compared to 48.1% in 1998, 58.9% in 2001, and 58.4% in 2007.

To guarantee absolute anonymity for participating physicians, a lawyer served as a trusted third party between responding physicians, researchers and the Flemish Agency for Care and Health, ensuring that completed questionnaires could never be linked to a particular patient or physician.

3.3. Questionnaire

The repeatedly validated questionnaire on end-of-life decision-making first asked whether death had been sudden and unexpected. If answered negatively – and an end-of-life decision could thus not be precluded – physicians were asked about the medical decisions made at the end of the patient's life with a possible or certain life-shortening effect.

We identified cases as euthanasia or assisted suicide if the physician gave an affirmative answer to the following questions: (1) Was the death the consequence of the use of drugs administered, supplied or prescribed with the explicit intention of hastening death or of enabling the patient to end his or her own life? (2) Was the decision made at the explicit request of the patient? The act was classified as euthanasia or assisted suicide depending on whether the patient self-administered the drugs.

Details about the decision-making process, the types of drugs used and the estimated degree of life-shortening according to the physician were also asked. Further in the questionnaire, physicians were asked whether palliative care services had been involved at the end of life and whether the patient had made a request for euthanasia that was not granted. Demographic and clinical patient data were obtained from the death certificate data and linked anonymously after data collection.

3.4. Analysis

The response sample was first corrected for disproportionate stratification (by weighting each stratum to make the proportion in the response sample identical to the proportion in all deaths) and adjusted to be representative of all deaths in the first half of 2013 in terms of age, sex, marital status, province of death, cause

of death and place of death (adjustments were needed for province of death and place of death). After this weighting procedure there were no significant differences between response sample and all deaths on any of these variables. Final weights varied between 0.11 and 1.90. The same procedure was used in all survey years (in 1998 there was no disproportionate stratification).

3.5. Ethics approval

Ethics approval was obtained from the Ethical Review Board of the University Hospital of the Vrije Universiteit Brussel. The mailing and anonymity procedures were also approved by the Belgian National Disciplinary Board of Physicians and by the Federal Privacy Commission.

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PART II

TRENDS IN EUTHANASIA PRACTICE

Chapter 3

Euthanasia in Belgium: trends in reported cases between 2003 and 2013

Sigrid Dierickx, Luc Deliens, Joachim Cohen, Kenneth Chambaere

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Abstract

Background – In 2002, the Belgian Act on Euthanasia came into effect, regulating the intentional ending of life by a physician at the patient’s explicit request. We undertook this study to describe trends in officially reported euthanasia cases in Belgium with regard to patients’ sociodemographic and clinical profiles, as well as decision-making and performance characteristics.

Methods – We used the database of all euthanasia cases reported to the Federal Control and Evaluation Committee on Euthanasia in Belgium between Jan. 1, 2003, and Dec. 31, 2013 ($n = 8752$). The committee collected these data with a standardized registration form. We analyzed trends in patient, decision-making and performance characteristics using a χ^2 technique. We also compared and analyzed trends for cases reported in Dutch and in French.

Results – The number of reported euthanasia cases increased every year, from 235 (0.2% of all deaths) in 2003 to 1807 (1.7% of all deaths) in 2013. The rate of euthanasia increased significantly among those aged 80 years or older, those who died in a nursing home, those with a disease other than cancer and those not expected to die in the near future ($p < 0.001$ for all increases). Reported cases in 2013 most often concerned those with cancer (68.7%) and those younger than 80 years (65.0%). Palliative care teams were increasingly often consulted about euthanasia requests, beyond the legal requirements to do so ($p < 0.001$). Among cases reported in Dutch, the proportion in which the person was expected to die in the foreseeable future decreased from 93.9% in 2003 to 84.1% in 2013, and palliative care teams were increasingly consulted about the euthanasia request (from 34.0% in 2003 to 42.6% in 2013). These trends were not significant for cases reported in French.

Interpretation – Since legalization of euthanasia in Belgium, the number of reported cases has increased each year. Most of those receiving euthanasia were younger than 80 years and were dying of cancer. Given the increases observed among non–terminally ill and older patients, this analysis shows the importance of detailed monitoring of developments in euthanasia practice.

1. Introduction

In 2002 Belgium legalized euthanasia, defined as the intentional ending of life by a physician at the patient's explicit request.^{1,2} For a patient to be eligible for euthanasia, certain formal criteria for due care have to be met.¹ These include a voluntary, well considered, repeated and written request expressed by a person with full mental capacity who is fully informed about his or her medical condition and remaining therapeutic possibilities.¹ The person must be in a state of constant and unbearable physical or mental suffering that cannot be alleviated. Procedural due care criteria include an a priori consultation with a second independent physician, consultation with a third physician in cases where death is not expected in the foreseeable future and a posteriori reporting of the case for evaluation purposes.¹

To safeguard due process and legal compliance and to enable societal control and evaluation, a mandatory notification procedure was built into the legislation.³ Physicians are required to report each case of euthanasia to the multidisciplinary Belgian Federal Control and Evaluation Committee for Euthanasia by completing and submitting a registration form within four working days after death by euthanasia.^{1,3} The Committee reviews the form and determines whether euthanasia was performed in accordance with the legal requirements. Initially, only anonymous information is reviewed; where there is doubt about legality, the Committee can revoke anonymity by majority decision and can ask the reporting physician for additional information. If the Committee is of the opinion, based on a two-thirds majority, that the legal requirements were not fulfilled, the case is sent to the public prosecutor.^{1,3} Although not mentioned in the Belgian law, physician-assisted suicide is treated as a form of euthanasia by the Committee.⁴

To facilitate societal control, the Committee is legally required to issue biennial reports of all reported cases,^{1,3-9} providing basic statistics, an evaluation of the law and further recommendations. However, these statistics do not provide an overview of long-term trends. A more complete and thorough evaluation of case characteristics and analysis of trends is needed. In this way, adherence to the legal criteria can be evaluated, and developments in euthanasia practice that might raise concerns can be identified and addressed.

Belgium has two main language communities: those who speak Dutch (roughly 60% of the population), who mainly live in Flanders, and those who speak French (about 40%), who mainly live in Wallonia. The Brussels-Capital Region is officially bilingual, but predominantly French-speaking. Several empirical

studies have found differences in end-of-life practices, knowledge and attitudes between the regions and language communities, showing that Dutch-speaking physicians more often receive and grant euthanasia requests and are more inclined to adhere to legal safeguards.^{10–14} The reports issued by the Committee show a striking disparity in euthanasia reporting between the two language communities.^{4–9} Trends in the characteristics of reported cases and differences among them have not yet been studied.

The Committee's reports show a continuing increase in the number of euthanasia cases.^{4–9} The primary objective of this study was to examine changes in the number and incidence of euthanasia cases and the proportion of euthanasia cases relative to all deaths in Belgium up to and including 2013. The secondary objectives were to determine and report the sociodemographic and clinical characteristics of patients, the decision-making and performance characteristics of reported cases and the differences in trends in characteristics between cases reported in Dutch and cases reported in French.

2. Methods

2.1. Data source and extraction of data

We obtained the data presented here from the database of officially reported euthanasia cases in Belgium, made available to us by the Federal Control and Evaluation Committee for Euthanasia. This database contains information routinely collected from the official standardized euthanasia registration forms submitted by the reporting physicians (see Appendix 1 for the English version of the registration form [authors' translation]). Physicians are contacted by the Committee when important information is missing.

We studied all reported cases of euthanasia that occurred between January 1, 2003 and December 31, 2013. Data for euthanasia cases reported in 2014 and 2015 were not included because the Committee's summary report for those years had not yet been published. The data are collected for evaluation and control purposes, and the Belgian euthanasia law allows for these data to be made available, on an anonymous basis, for academic research purposes, upon reasoned request to the Committee.¹

The registration form was developed by the Committee and consists of two parts.^{1,3} The first part is confidential and includes the identities of the patient, the attending physician and the consulted physician(s). The Committee may not use

this part of the document for evaluation but may decide, by majority, to revoke anonymity and contact the physician for further information in case of irregularities. The second part contains specifications about the age, sex and diagnosis of the person receiving euthanasia, the type of and reasons for the request, the place and date of death, and the euthanasia procedure followed. The Committee uses this part to determine whether the performance of euthanasia was in accordance with the conditions and procedures stipulated by law. Further details about the registration form and its items have been described elsewhere.³

The registration form contains both open-ended and closed-ended questions with pre-structured response categories. In the database we received, the open-ended questions were encoded into categories by the Committee. We checked the data for coding quality and, if necessary, recoded to obtain consistency over the years in coding of variables. Inconsistencies in the data were checked and clarified with the Committee.

2.2. Statistical analysis

Trends in demographic, clinical and decision-making characteristics were tested using χ^2 linear-by-linear association statistics to calculate bivariable *p* values. All analyses were performed using SPSS software, version 23.0.

2.3. Ethics approval

We obtained ethical approval from the Ethical Review board of the University Hospital Brussels.

3. Results

Between January 1, 2003 and December 31, 2013, a total of 8,752 euthanasia cases were reported (Figure 3.1). The number increased yearly from 235 in 2003 (0.2% of all deaths in 2003) to 1,807 cases in 2013 (1.7% of all deaths in 2013) (Table 3.1). The proportion of euthanasia in all deaths rose in all patient subgroups and was consistently highest in those with cancer, younger than 80 years and dying at home.

Between 2003 and 2013, the proportion of cases involving patients aged 80 years or older increased from 17.0% to 35.0% ($p < 0.001$), while the proportion of cases involving those aged 18 to 59 decreased from 34.5% to 16.5% ($p < 0.001$) (Table 3.2). An increasing proportion of euthanasia cases involved people in a nursing home (from 5.1% to 12.1%, $p < 0.001$) and people with a diagnosis other than cancer (from 15.7% to 31.3%, $p < 0.001$), while there were decreases in the proportion of cases involving those dying in hospital (from 52.3% to 42.6%, $p < 0.001$) and those with a diagnose of cancer (from 84.3% to 68.7%, $p < 0.001$) decreased. The proportion of euthanasia cases among those who were expected to die in the foreseeable future decreased from 91.9% to 85.3% ($p < 0.001$).

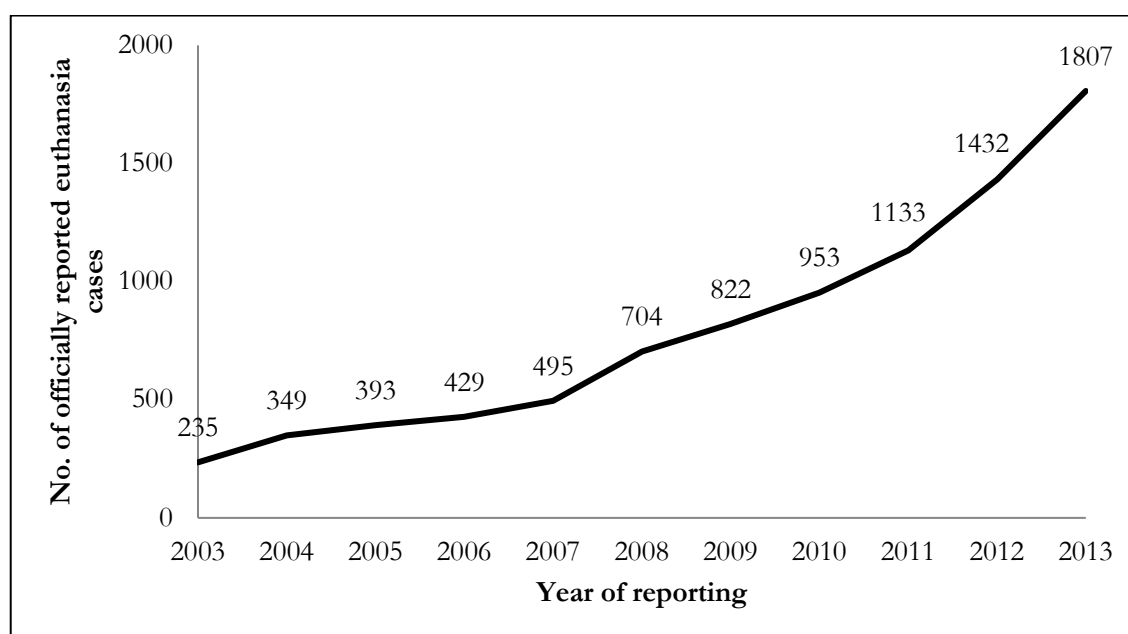


Figure 3.1 Number of officially reported cases of euthanasia in Belgium, 2003-2013

Between 2003 and 2013, the proportion of cases involving patients aged 80 years or older increased from 17.0% to 35.0% ($p < 0.001$), while the proportion of cases involving those aged 18 to 59 decreased from 34.5% to 16.5% ($p < 0.001$) (Table 3.2). An increasing proportion of euthanasia cases involved people in a nursing home (from 5.1% to 12.1%, $p < 0.001$) and people with a diagnosis other than cancer (from 15.7% to 31.3%, $p < 0.001$), while there were decreases in the proportion of cases involving those dying in hospital (from 52.3% to 42.6%, $p < 0.001$) and those with a diagnose of cancer (from 84.3% to 68.7%, $p < 0.001$) decreased. The proportion of euthanasia cases among those who were expected to die in the foreseeable future decreased from 91.9% to 85.3% ($p < 0.001$).

Table 3.1 Characteristics of deaths in Belgium officially reported as euthanasia, relative to all deaths, 2003-2013^a

	Year: euthanasia cases as % of all deaths ^b										
	2003	2004	2005	2006	2007	2008	2009	2010	2011	2012	2013
Total no. of deaths	107.039	101.946	103.278	101.587	102.060	104.587	104.509	105.094	104.247	109.034	109.295
Incidence of euthanasia per 100.000	2.3	3.4	3.8	4.1	4.7	6.6	7.6	8.8	10.3	13.0	16.3
Overall	0.2	0.3	0.4	0.4	0.5	0.7	0.8	0.9	1.1	1.3	1.7
Sex											
Male	0.2	0.4	0.4	0.5	0.5	0.7	0.8	1.0	1.1	1.4	1.7
Female	0.2	0.3	0.4	0.4	0.4	0.6	0.8	0.8	1.1	1.3	1.6
Age, yr											
18-59	0.6	0.8	0.8	1.0	1.0	1.2	1.5	1.7	1.6	2.3	2.5
60-79	0.3	0.5	0.5	0.6	0.8	1.0	1.1	1.4	1.6	1.9	2.5
80 or older	0.1	0.1	0.1	0.2	0.2	0.3	0.4	0.4	0.6	0.8	1.0
Diagnosis											
Cancer	0.7	1.1	1.2	1.3	1.5	2.0	2.3	2.6	2.9	3.7	4.3
Other than cancer	0.05	0.1	0.1	0.1	0.1	0.1	0.2	0.3	0.4	0.5	0.7
Place of death											
Home	0.4	0.5	0.6	0.7	1.0	1.2	1.5	1.8	2.1	2.4	3.1
Hospital	0.2	0.4	0.4	0.4	0.5	0.6	0.7	0.8	1.0	1.2	1.5
Nursing home	0.1	0.1	0.1	0.1	0.1	0.2	0.2	0.2	0.4	0.5	0.8
Other	0.1	0.3	0.4	0.4	0.3	0.7	1.2	0.7	0.7	0.9	0.6

^aData on the number of deaths were obtained from Statistics Belgium. As the euthanasia law came into force on September 23, 2002¹ the data from that year are excluded from analysis, as these do not cover an entire year. A total of 24 cases were reported in that period.

^bExcept where indicated otherwise.

Table 3.2 Trends in patient characteristics of reported euthanasia cases in Belgium, 2003-2013^a

	Year, % of euthanasia cases										Average annual change, %	P value ^b	
	2003 (n=235)	2004 (n=349)	2005 (n=393)	2006 (n=429)	2007 (n=495)	2008 (n=704)	2009 (n=822)	2010 (n=953)	2011 (n=1133)	2012 (n=1432)			2013 (n=1807)
Sex													
Male	49.4	52.1	51.9	53.8	54.3	52.3	49.4	53.9	50.6	51.1	52.0	+0.3	.7
Female	50.6	47.9	48.1	46.2	45.7	47.7	50.6	46.1	49.4	48.9	48.0	-0.3	
Age, yr													
18-59	34.5	28.9	27.2	29.6	26.1	22.7	24.1	21.6	17.7	19.5	16.5	-1.8	<.001
60-79	48.5	52.4	53.4	52.2	56.8	52.6	51.1	52.4	51.6	48.5	48.5	0.0	.006
80 or older	17.0	18.6	19.3	18.2	17.2	24.7	24.8	26.0	30.7	32.0	35.0	+1.8	<.001
Place of death													
Hospital	52.3	55.9	51.7	52.4	47.3	47.0	43.7	44.9	44.7	45.4	42.6	-1	<.001
Home	41.3	37.8	40.5	42.0	47.3	43.0	45.6	46.3	44.4	42.4	44.3	+0.3	.1
Nursing home	5.1	4.3	5.6	3.0	4.2	7.8	7.4	6.3	8.9	10.4	12.1	+0.7	<.001
Other	1.3	2.0	2.3	2.6	1.2	2.1	3.3	2.5	1.9	1.8	1.1	-0.02	.09
Diagnosis													
Cancer	84.3	81.7	85.0	81.4	81.8	80.1	78.0	78.4	72.4	73.6	68.7	-1.6	<.001
Other than cancer	15.7	18.3	15.0	18.6	18.2	19.9	22.0	21.6	27.6	26.4	31.3	+1.6	
Progressive neuromuscular disorder	7.8	7.7	4.3	7.5	8.7	6.1	6.4	6.8	6.9	4.9	6.3	-0.2	.1
Nonprogressive neuromuscular disorder	3.0	0.3	1.5	0.2	0.8	1.1	0.6	1.0	0.5	0.8	0.4	-0.3	.009
Nonmalignant pulmonary disorder	0.9	1.1	3.3	2.8	1.2	2.6	3.5	1.7	3.9	2.9	3.9	+0.3	.001
Cardiovascular disorder	2.6	3.4	1.3	2.1	2.6	3.1	3.9	5.1	5.5	4.8	5.9	+0.3	<.001
AIDS	0.0	0.9	0.3	0.5	0.2	0.0	0.0	0.1	0.0	0.1	0.1	+0.01	.003
Kidney disorder	ε	ε	0.0	0.9	0.2	0.4	0.6	0.3	0.6	0.8	0.7	+0.07	.02
Nonmalignant digestive disorder	ε	ε	0.3	0.0	0.0	0.6	0.2	0.3	0.5	0.5	0.6	+0.03	.007
Neuropsychiatric disorder	ε	ε	0.8	1.2	0.8	1.8	2.6	2.6	2.9	3.7	3.9	+0.3	<.001
Multiple pathologies	ε	ε	2.5	0.5	2.0	1.7	2.1	1.7	2.0	4.1	5.9	+0.3	<.001
Other	1.3	4.9	0.8	2.8	1.6	2.4	2.1	1.9	4.8	3.9	3.7	+0.2	.001
Death expected in foreseeable future	91.9	93.1	93.1	93.9	94.3	93.0	91.8	91.6	89.9	88.3	85.3	-0.7	<.001
Reported suffering													
Physical and psychological suffering	50.6	61.2	57.0	70.7	78.2	84.6	78.0	74.2	70.0	63.5	68.5	+1.8	.5
Only physical suffering	42.4	34.4	37.6	27.9	20.8	13.6	18.1	22.3	26.6	28.9	27.8	-1.5	.1
Only psychological suffering	6.9	4.4	5.4	1.4	1.0	1.9	3.9	3.6	3.4	7.5	3.7	-0.3	.03

^aData for 2002 were excluded from analysis because the euthanasia law came into force on September 23, 2002 and data for 2002 thus represent less than an entire year. A total of 24 cases were reported from September 23 to December 31, 2002.

^bBased on χ^2 linear-by-linear association statistics.

^cFor 2003 and 2004, kidney disorder, nonmalignant digestive disorder and multiple pathologies were assigned to the category "other".

Table 3.3 Trends in decision-making and performance characteristics of reported euthanasia cases in Belgium, 2003-2013^a

Characteristics	2003 (n=235)	2004 (n=349)	2005 (n=393)	2006 (n=429)	2007 (n=495)	2008 (n=704)	2009 (n=822)	2010 (n=953)	2011 (n=1133)	2012 (n=1432)	2013 (n=1807)	Average annual change, %	p value ^b
Type of request for euthanasia													
Current request	99.6	98.6	98.0	96.0	98.2	98.0	97.2	97.5	97.8	96.9	98.7	-0.1	.95
Advance directive ^c	0.4	1.4	2.0	4.0	1.8	2.0	2.8	2.5	2.2	3.1	1.3	+0.1	
Specialty of second physician^d													
Specialist palliative care physician	19.1	15.5	10.7	10.0	8.7	10.1	10.4	10.2	9.6	13.8	11.0	-0.8	.3
General practitioner	34.9	41.7	42.5	44.4	48.4	46.3	51.2	49.8	50.7	50.1	52.4	+1.8	<.001
Disease or organ specialist	46.0	42.9	46.8	45.6	42.9	43.6	38.4	40.0	39.6	36.1	36.6	-0.9	<.001
Specialty of third physician, if required^e (n=867)													
Psychiatrist	68.4	41.7	66.7	57.7	67.9	77.6	62.7	68.8	67.9	74.3	68.9	+0.1	.06
Disease or organ specialist	31.6	58.3	33.3	42.3	32.1	22.4	37.3	31.3	32.1	25.7	31.1	-0.1	
Consultations beyond legal requirements													
Additional physician or palliative care team	80.3	55.3	53.9	50.6	59.2	55.5	56.0	52.4	52.3	53.3	50.7	-3.0	<.001
Additional physician	37.9	38.1	34.1	28.0	34.5	33.2	29.9	26.8	26.5	26.4	25.0	-1.3	<.001
Palliative care team ^g	33.9	33.8	31.3	32.4	39.4	38.1	41.1	40.6	38.0	39.9	39.3	+0.5	.001
Drugs used to perform euthanasia^f													
Barbiturate IV, with or without neuromuscular relaxant	80.0	85.1	92.1	94.2	96.0	98.2	98.2	99.2	98.8	99.1	98.7	+1.9	<.001
Barbiturate per os, with or without neuromuscular relaxant	1.8	1.7	1.0	2.8	2.4	1.0	0.9	0.3	0.8	0.4	1.0	-0.1	<.001
Other or unclear from registration form ^h	18.2	13.2	6.9	3.0	1.6	0.9	1.0	0.5	0.4	0.5	0.3	-1.8	<.001

Note: IV=intravenous.

^aData for 2002 were excluded from analysis because the euthanasia law came into force on September 23, 2002 and data for 2002 thus represent less than an entire year. A total of 24 cases were reported from September 23 to December 31, 2002.^bBased on χ^2 linear-by-linear association statistics.^cEuthanasia based on an advance euthanasia directive is allowed only if the person is in an irreversible coma.^dThe attending physician must consult a second, independent physician about the serious and incurable character of the disorder. Information about this aspect is ascertained by an open-ended question on the registration form. ^eBelgian law distinguishes between persons who are expected to die in the foreseeable future and those who are not expected to die in the foreseeable future. For the latter, a third physician must be consulted. The third physician should be either a psychiatrist or a specialist in the patient's illness.^fData on whether palliative care teams were consulted and on the drugs used to perform euthanasia were available for only 56 of the 235 cases in 2003.^gPalliative care consultation is not legally required, palliative teams can however be consulted about euthanasia requests beyond the legal requirements.^hOther drugs included midazolam, morphine, and other drugs used to induce unconsciousness.

Over the study period, general practitioners were consulted increasingly often as the second physician (from 34.9% to 52.4%, $p < 0.001$) and disease and organ specialists less often (from 46.0% to 36.6%, $p < 0.001$) (Table 3.3). The proportion of cases in which an additional physician was consulted, beyond the legal requirements for consultation, decreased from 37.9% to 25.0% ($p < 0.001$), whereas the proportion of cases in which at least one palliative care team was consulted about the request increased from 33.9% to 39.3% ($p = 0.001$). The use of barbiturates by intravenous administration for euthanasia increased significantly, from 80.0% to 98.7% of cases ($p < .001$).

Most cases were reported in Dutch; the yearly proportion ranged between 79.3% and 87.1% of all reported cases over the study period, with a significant decrease over time, from 84.3% in 2003 to 80.5% in 2013 ($p = 0.007$) (data not shown). In 2013, euthanasia cases reported in French, relative to those reported in Dutch, more often occurred in hospital (52.1% v. 40.3%, $p < 0.001$) and less often at home (38.0% v. 45.8%, $p < 0.009$). Among cases reported in French, patients were more often expected to die in the foreseeable future than among cases reported in Dutch (90.1% v 84.1%, $p = 0.004$), physical suffering was more often accompanied by psychologic suffering (77.0% v. 66.4%, $p < 0.001$), and palliative teams were less often consulted about the request (25.8% v. 42.6%, $p < 0.001$) (data not shown).

Trends in prognosis and in consultation with palliative care teams about the euthanasia request differed between cases reported in Dutch and in French (data not shown). Among cases reported in Dutch, the proportion in which the person was expected to die in the foreseeable future decreased significantly, from 93.9% in 2003 to 84.1% in 2013, and Dutch-speaking physicians increasingly consulted palliative care teams about the euthanasia request (34.0% in 2003 and 42.6% in 2013). These trends were not significant for cases reported in French.

4. Interpretation

Based on data collected by the Belgian Federal Control and Evaluation Committee for Euthanasia, this study provides insight into trends in the highly debated practice of euthanasia in Belgium. Adding to the data from cross-sectional surveys on Belgian euthanasia practice¹⁵⁻¹⁹, the current study provides year-by-year time trends from a population-based perspective for all euthanasia cases officially reported since implementation of the Belgian euthanasia law in

2002. In contrast, recent studies on euthanasia in Belgium have been limited to Flanders, the northern Dutch-speaking part of Belgium. In addition, the current study examines differences in time trends in the reporting of euthanasia between Dutch- and French-speaking physicians.

Our analyses showed that the number of officially reported euthanasia cases increased each year (from 235 in 2003 to 1,807 in 2013), in both sexes, across all age groups, among those with cancer and diseases other than cancer, and in all care settings. The highest incidence was consistently found among people dying with cancer, those younger than 80 years of age and those dying at home. Among reported cases, the proportions involving patients aged 80 years or older, those dying in a care home setting, those dying of a disease other than cancer and those not having a terminal diagnosis increased, the latter particularly for cases reported in Dutch. Palliative care teams were increasingly consulted about the euthanasia request, beyond the legal requirements to do so, especially for cases reported in Dutch. Our findings showed an increase in euthanasia among older persons and patients without terminal disease in the most recent years, whereas such cases were relatively rare in the first years of the euthanasia law. These findings might suggest an increase in the number of requests from these groups as they increasingly became aware of the legal possibility to request euthanasia. These findings might also reflect a decrease in reluctance to provide euthanasia within these groups as physicians became more experienced and the wider society became more familiar these types of cases. We deem it less plausible that the trends indicate more vulnerable groups feeling increasingly forced to choose euthanasia. Moreover, all of the cases included in our analysis were approved by the Committee, which implies a careful evaluation of each request being without any external pressure.

Given the annual increase in reported cases after legalization in Belgium, as described here, as well as in the Netherlands²⁰, it can be assumed that overburdening of the Belgian review committee may pose a problem, now or in the future. The Dutch review committees have already taken measures to address the increase in reported cases by implementing a new review method, which includes a preliminary screening to separate potentially contentious cases and less contentious cases.²¹ It is desirable that review systems incorporate capacity measures that anticipate increases in reported cases, to guarantee the ability to perform the monitoring function.

The increase in the number of reported euthanasia cases in Belgium is corroborated by a nationwide survey on medical end-of-life practices in Flanders,

which found an increase in the euthanasia rate from 1.9% of all deaths in 2007 to 4.6% in 2013.¹⁶ These data suggest an increase in the prevalence of euthanasia and not just in the reporting rate. Our study of reported cases also corroborates the results of that survey showing increases in groups that were previously less likely to request or receive euthanasia, such as older persons and those with diseases other than cancer.^{16,17} The gradual increase in acceptance of euthanasia within society is a likely reason for these changes. In the early years after legalization physicians seem to have been more reluctant to grant euthanasia in cases of diseases other than of cancer, perhaps because of uncertainty about its legality in such cases. Experience with the practice, reassurance through lack of prosecutions (with the first case since legalization being sent to the public prosecutor for judicial review only in October 2015), media reporting on controversial cases and ensuing public debate about the interpretation of legal criteria such as “incurable disorder” and “unbearable physical or psychological suffering” are likely to have contributed to a broadening of the previously narrow interpretation of the legal criteria. The increase in euthanasia in cases with noncancer diagnoses and nonterminal diseases emphasizes the importance of thorough evaluation and monitoring of the practice since these situations are often more complex and include psychiatric disorders and “tiredness of life”.

The development of assisted dying has differed from one country to another. The Netherlands, Belgium, Luxembourg, Switzerland, Colombia and five American states (Oregon, Washington, Montana, Vermont and California) allow some form of physician-assisted dying.²² Official reports from Oregon, Vermont and Washington, where only physician-assisted suicide is legal and euthanasia is not, have also shown an increase in the number of officially reported deaths, although with much lower incidences than in Belgium and the Netherlands.^{22–27} Even within Belgium, development of the practice has differed between Flanders and Wallonia, as our study shows. The relative underrepresentation of reported euthanasia cases from the French-speaking community and the differences in case characteristics corroborate previous studies that found significant differences between Flanders and Wallonia in terms of practice, attitudes and knowledge about euthanasia.^{10–12,14} These differences suggest that euthanasia legislation does not have a predetermined effect on medical end-of-life practice and that social and cultural elements also influence its development.

Several specific factors may have contributed to development of the practice in Flanders. The existence of the Life’s End Information Forum in Flanders may have led to increased knowledge about euthanasia and standardized procedures in practice by providing advice on assisted dying and other end-of-life issues.²⁸

The Life's End Information Forum also provides specially trained physicians to act as the legally required second physician, which has been shown to contribute to the careful practice of euthanasia.^{29,30} A similar service, Forum End Of Life, has been established in French-speaking Belgium, but it is more limited and less formalized. In addition, palliative care services are involved in Flemish euthanasia practice to a large extent¹⁶, offering support during the decision-making process and during the performance of euthanasia. Moreover, the viewpoint of euthanasia as part of the palliative care continuum has been endorsed by the Federation of Palliative Care Flanders.^{31,32} The present study found an increase in consultation of palliative teams about the euthanasia request from 33.9 per cent of all cases in 2003 to 39.3 per cent in 2013. The reporting form does not record whether patients had previously received palliative care. Thirdly, over the years the topic of euthanasia has received considerable attention in Flemish mainstream media and is an important issue of public debate.³³

5. Limitations

Some limitations have to be taken into account. Firstly, the data only provide insight into reported euthanasia cases. Previous research conducted in 2007 in Belgium found that approximately half of all euthanasia cases are reported to the Committee and that unreported cases were generally dealt with less carefully than reported cases.³⁴ Secondly, this study is based on analysis of secondary data collected as part of the mandatory notification procedure. Details about the patient's clinical circumstances and the precise nature of their suffering that caused them to seek euthanasia were not recorded in the database.

6. Conclusion

The practice of euthanasia in Belgium has increased year by year since the introduction of legislation in 2002. An increase in cases often considered as more controversial, such as those with neuropsychiatric conditions, has also occurred although these remain a small minority. Given the different developments found between jurisdictions and even within Belgium, it is clear that societal and cultural contexts play a key part in how euthanasia practice is adopted after legalization. Our analysis shows the importance of detailed monitoring of euthanasia practice,

Chapter 3

provides relevant insights for evaluation of the practice, and can inform the debate about euthanasia worldwide.

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Chapter 4

Comparison of the expression and granting of requests for euthanasia in Belgium in 2007 vs 2013

Sigrid Dierickx, Luc Deliens, Joachim Cohen, Kenneth Chambaere

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Abstract

Importance – Since 2002 physicians in Belgium have legally been able to grant euthanasia requests. However, not every request leads to euthanasia being performed.

Objective – To study the shifts in expressing and granting euthanasia requests between 2007 and 2013 in Flanders, Belgium and to investigate the reasons Flemish physicians report for deciding to grant or reject these requests.

Design, setting and participants – We conducted a population-based death certificate study in Flanders, Belgium in 2013, identical to a survey in 2007, among attending physicians of a stratified random sample of 6,871 deaths. Response samples were weighted to be representative of all deaths for various demographic and clinical variables.

Main outcomes and measures – Prevalence of euthanasia, expressed euthanasia requests and granting rates, and the most important reasons for granting or not granting a request.

Results – Response rate was 60.6%. The percentage of deaths with a euthanasia request rose from 3.4% in 2007 to 5.9% in 2013 ($P < .001$) while granting rates rose from 55.4% to 76.7% ($P < .001$). The most pronounced increases in the number of requests were found in patients aged 80 or older (relative risk [RR] of 2013 vs. 2007, 2.2 [95%CI, 1.5-3.3]), those with a college/university degree (RR, 2.9 [95%CI, 1.4-6.1]) and those diagnosed with cardiovascular disease (RR, 3.9 [95%CI, 1.4-10.9]). Granting rates rose most among those aged 80 or older (RR, 2.0 [95%CI, 1.3-3.1]), those with lower levels of education (RR, 2.0 [95%CI, 1.1-3.6]), and those dying in nursing homes (RR, 3.0 [95%CI, 1.3-6.9]). The most important reasons for granting the request in 2013 were the patient's request, physical and/or mental suffering and lack of prospects for improvement. The proportion of deaths where the physician did not grant the request for reasons external to the patient, such as institutional policy, the physician's personal objections or fear of legal consequences, decreased significantly from 23.4% to 2.0% ($P = .003$).

Conclusion and relevance – The proportion of dying patients who make a euthanasia request has substantially increased across various patient groups and, following 11 years of experience with the practice, physicians are more willing to grant these requests.

1. Introduction

In recent decades, substantial changes have emerged in end-of-life care due to a considerable amount of deaths preceded by long-term and progressive illness and the increasing influence of medical-technological interventions.^{1,2} Personal autonomy, maintenance of independence and being in control are considered to be important aspects of a 'good death' in modern western society.²⁻⁴ In addition to prolonging life, preserving quality of life is nowadays recognized as an important goal in end-of-life care. As a consequence, medical end-of-life decisions have become a substantial part of contemporary medical practice.⁵⁻¹² These can include explicit requests for euthanasia (i.e. the administration of drugs with the explicit intention to end the patient's life at the patient's explicit request) or physician-assisted suicide (i.e. the prescription of lethal medication for the patient to self-administer).

Physicians can legally grant euthanasia requests in three countries, Belgium and the Netherlands since 2002 and Luxembourg since 2009. Physician-assisted suicide is possible in the Netherlands, Luxembourg, Switzerland and five US states (Oregon, Washington, Montana, Vermont and New Mexico). Legalization of physician-assisted suicide is currently being considered in other US states and a number of countries, including Canada and the UK.^{13,14} Research from countries where assisted dying is legal has shown that not every request eventually leads to euthanasia.¹⁵⁻¹⁸ Patients can withdraw their request, can die before a decision is made or the request can be denied (for reasons of eligibility criteria or physician/institutional characteristics).

To guarantee careful practice, handling euthanasia requests is subjected to a number of formal criteria and procedural requirements for due care. The Belgian euthanasia law states that a patient has to make a voluntary, repeated, well-considered and written request not expressed under any external pressure.^{19,20} Furthermore, the patient must be in a medically hopeless condition of constant and unbearable physical or psychological suffering due to a serious and incurable disorder caused by an accident or illness.

Between 2007 and 2103, the prevalence of euthanasia in Flanders, the Dutch-speaking part of Belgium, increased from 1.9% to 4.6% of all deaths.¹² A major concern with assisted dying is that legalization would increase euthanasia in vulnerable patient groups such as elderly people and those with lower levels of education. As previous research has shown that assisted dying is generally

practiced in younger persons, the highly educated and in cancer patients, these concerns remain uncorroborated^{8,10,21,22}.

This study aims to describe the shifts (overall and in specific groups of patients) in the expression and granting of euthanasia requests and the reasons that granted or denied these requests. We compare two identical surveys conducted after the legalization of euthanasia in 2002 i.e. in 2007 and 2013. The following research questions are posed:

1. What is the proportion of decedents with a euthanasia request expressed and/or granted within specific patient groups and what shifts occurred between 2007 and 2013?
2. What are the most important reasons for granting or not granting a euthanasia request and what shifts can be identified between 2007 and 2013?

2. Methods

2.1. Death certificate study

We conducted a nationwide postal questionnaire survey in 2013 that was identical to a survey conducted in 2007^{8,10}, based on a large and representative sample of deaths in Flanders, the semi-autonomous northern half of Belgium with approximately six million inhabitants and on average 58,000 deaths annually. A stratified random sample of deaths in 2013 was drawn weekly at the Flemish Agency for Care and Health, the central administration authority for processing death certificates. All deaths from January 1st until June 30th, 2013 of Belgian residents aged one year or older were assigned to one of three strata, based on underlying cause of death as indicated on the death certificate and the estimated corresponding likelihood of an end-of-life decision. Sampling fractions for each stratum increased with this likelihood. In the first stratum, all deaths for which euthanasia was mentioned on the death certificate were sampled. In the second stratum, one third of all cancer deaths were sampled. In the third stratum, one in six deaths resulting from any other cause was sampled. This resulted in a sample of 6871 deaths, about 21% of all deaths in the studied period.

Within two months of the death, certifying physicians received a four-page questionnaire with an introductory letter containing patient identifiers. Physicians

were requested to complete the questionnaire consulting the patient's medical file. If the certifying physician was not the treating physician, the questionnaire was passed on to the treating physician. One physician could receive participation requests for up to five decedents, with at most three reminders per death. To guarantee absolute anonymity for participating physicians, a lawyer served as an intermediary between responding physicians, researchers and the Flemish Agency for Care and Health, ensuring that completed questionnaires could never be linked to a particular patient or physician. After data collection, a one-page questionnaire was mailed to all non-responding physicians, inquiring about reasons for not participating. The mailing and anonymity procedure were approved by the Ethical Review Board of the University Hospital of the Vrije Universiteit Brussel, the Belgian National Disciplinary Board of Physicians, and the Belgian Privacy Commission. Patients were deceased, so no consent could be obtained. Physicians' participation was regarded as implicit consent.

2.2. Questionnaire

The repeatedly validated questionnaire on end-of-life decision-making first asked whether death had been sudden and unexpected. If answered negatively – and an end-of-life decision could thus not be precluded – physicians were asked whether they had: (1) withheld or withdrawn life-prolonging medical treatment taking into account or explicitly intending to hasten the patient's death; (2) intensified the alleviation of pain and/or other symptoms with drugs taking into account or co-intending possible hastening of death and (3) administered, supplied or prescribed drugs with the explicit intention of hastening death. If in the latter case the drugs had been administered at the patient's explicit request, the act was classified as euthanasia or assisted suicide depending on whether the patient self-administered the drugs. Further in the questionnaire, physicians were asked what the most important reasons were for granting a request. If a patient made a euthanasia request that was not granted, the physicians were asked to indicate the reasons for not granting the request. Demographic and clinical patient data were obtained from the death certificate and linked anonymously after data collection.

2.3. Analysis

The response sample was first corrected for disproportionate stratification (by weighting each stratum to make the proportion in the response sample identical

to the proportion in all deaths) and adjusted to be representative of all deaths in the first half of 2013 in terms of age, sex, marital status, province of death, cause of death and place of death (adjustments were needed for province of death and place of death). After this weighting procedure, there were no significant differences between response sample and all deaths on any of these variables. Final weights varied between 0.11 and 1.90. This procedure was used in both survey years. We used the complex samples function in SPSS 22.0 to calculate weighted percentages, relative risk ratios, 95% confidence intervals, and Chi² (two-sided) *P* values.

3. Results

Of the 6871 deaths sampled, questionnaires were returned for 3751. From non-response analyses, we found that response was impossible for 683 deaths (e.g. because the physician did not have access to the patient's medical file or the patient could not be identified). Therefore, the response rate was 60.6% (3,751/6,188 eligible cases) compared with 58.4% (3623 of 3202 eligible cases) in 2007 (Table 4.1). The proportion of decedents aged 80 or older increased between 2007 and 2013 from 50.0% to 57.1% ($p < .001$). Cancer accounted for around one in four deaths. Compared with 2007, more people in 2013 died in nursing homes (from 22.7% to 27.0%; $p < .001$) while the number of deaths in hospitals decreased (from 50.4% to 47.7%; $p = .03$).

The prevalence of euthanasia increased in all patient groups and all health care settings (Table 4.2). The prevalence in 2013 was highest among college/university educated patients (11.2%), cancer patients (10.4%) and patients dying at home (8.1%). In decedents aged 80 or above, those with lower levels of education and those dying in nursing homes, a considerably higher prevalence of euthanasia was found in 2013 compared with 2007, although it remained lower than in other groups.

The overall increase in prevalence of euthanasia between 2007 and 2013 is related to significant increases in both the number of requests (from 3.4% to 5.9%; $p < .001$) and the proportion of those requests granted (from 55.4% to 76.7%; $p < .001$). The most pronounced increases in the number of requests were found in patients aged 80 or older (relative risk of 2013 vs. 2007 [RR], 2.2 [95%CI, 1.5-3.3]), college/university educated patients (RR, 2.9 [95%CI, 1.4-6.1]) and those diagnosed with cardiovascular disease (RR, 3.9 [95%CI, 1.4-10.9]). Granting rates

rose most among female patients (RR, 1.7 [95%CI, 1.3-2.2]), those aged 80 or older (RR, 2.0 [95%CI, 1.3-3.1]), those with lower educational levels (RR, 2.0 [95%CI, 1.1-3.6]), and those dying in nursing homes (RR, 3.0 [95%CI, 1.3-6.9]).

Table 4.1 Characteristics of decedents in Flanders, Belgium 2007 and 2013^a

	2007	2013	p-value ^b
Total annual deaths	54 881	61 621	
No. of deaths in survey sample	6202	6188	
Response %	58.4	60.6	
No. of studied cases	3623	3751	
Sex			
Male	1875 (49.8)	1920 (50.5)	.49
Female	1748 (50.2)	1826 (49.4)	.50
Unknown	0 (0.0)	5 (0.1)	
Age (in years)			
1-64	741 (17.2)	632 (15.5)	.05
65-79	1267 (32.7)	1100 (27.3)	<.001
80 or older	1615 (50.0)	2014 (57.1)	<.001
Unknown	0 (0.0)	5 (0.1)	
Educational attainment			
None or primary	1196 (35.5)	923 (25.8)	<.001
Lower secondary	692 (18.4)	639 (16.8)	.33
Higher secondary	523 (13.0)	594 (15.6)	<.001
College/University	203 (5.4)	184 (4.6)	.91
Unknown	1009 (27.7)	1411 (37.2)	
Cause of death			
Cardiovascular disease (incl. CVA ^c)	572 (33.7)	915 (30.3)	.003
Cancer	1923 (27.8)	1394 (25.0)	.01
Respiratory disease	331 (12.0)	303 (10.5)	.06
Disease of the nervous system	141 (3.6)	186 (5.4)	<.001
Other disease	656 (22.9)	930 (28.2)	<.001
Unknown	0 (0.0)	23 (0.7)	
Place of death			
At home	1308 (24.8)	1175 (23.3)	.13
In hospital	1406 (50.4)	1460 (47.7)	.03
In nursing home	857 (22.7)	1039 (27.0)	<.001
Other	51 (2.1)	71 (2.0)	.87
Unknown	1 (0.0)	6 (0.1)	

^aUnweighted number of cases (weighted column percentages).

^bBivariate p-value based on Fisher's Exact Test.

^cCVA=cerebrovascular accident.

Table 4.2 Shifts in euthanasia requests and granting rates (2013 vs 2007)^a

	% of deaths with euthanasia request			% dying with euthanasia			% of euthanasia requests granted			
	2007	2013	2013 vs 2007 Biv. P Value ^b	2007	2013	2013 vs 2007 Biv. P Value ^b	2007	2013	2013 vs 2007 Biv. P Value ^b	Relative risk (95% CI) ^c
Overall	3.4	5.9	<.001	1.9	4.6	<.001	55.4	76.7	<.001	1.4 (1.2-1.6)
Sex										
Male	3.6	5.9	.001	2.3	4.6	.006	64.1	76.9	.006	1.2 (1.0-1.5)
Female	3.2	6.0	<.001	1.5	4.6	<.001	45.7	76.4	<.001	1.7 (1.3-2.2)
Age										
1-64	6.4	8.2	.23	3.9	5.6	.02	61.9	68.1	.02	1.1 (0.8-1.4)
65-79	4.0	7.5	<.001	2.5	6.3	<.001	63.6	83.6	<.001	1.3 (1.0-1.7)
80 or older	2.0	4.6	<.001	0.8	3.4	<.001	38.1	75.4	<.001	2.0 (1.3-3.1)
Educational attainment										
None or primary	2.2	3.6	.05	0.8	2.5	<.001	35.1	69.5	<.001	2.0 (1.1-3.6)
Lower secondary	4.5	5.4	.52	3.0	3.8	.14	65.7	69.7	.14	1.1 (0.8-1.4)
Higher secondary	4.4	7.5	.04	2.6	5.6	.17	59.0	74.2	.17	1.3 (0.9-1.8)
College/University	4.5	12.9	.008	3.1	11.2	.11	68.9	86.3	.11	1.3 (0.8-1.9)
Cause of death										
Cardiovascular disease (incl. CVA)	0.8	3.0	<.001	0.2	2.2	.04	29.6	73.2	.04	2.5 (0.5-11.3)
Cancer	8.6	13.4	.001	5.6	10.4	<.001	64.4	77.5	<.001	1.2 (1.0-1.4)
Respiratory disease	1.6	2.4	.46	0.8	1.8	.28	47.1	72.7	.28	1.5 (0.6-4.1)
Disease of the nervous system	4.2	6.3	.46	2.9	6.3	.05	69.5	100	.05	1.4 (0.9-2.4)
Other disease	1.8	3.9	.009	0.3	2.7	<.001	18.8	70.7	<.001	3.8 (0.9-16.0)
Place of death										
At home	5.8	10.7	<.001	3.8	8.1	<.001	65.4	75.3	<.001	1.2 (1.0-1.4)
In hospital	2.8	5.0	.001	1.7	4.1	.009	59.1	82.4	.009	1.4 (1.1-1.8)
In nursing home	2.1	3.9	.02	0.5	2.7	<.001	22.9	68.2	<.001	3.0 (1.3-6.9)
Other	3.4	1.1	.62	0.0	0.2	.40	0.0	20.1	.40	^d

^a Weighted percentages.^b Bivariate P Value based on Fisher's Exact Test.^c Relative risk is calculated with the complex samples function in SPSS 22.0.^d Relative risk could not be calculated for requests granted in other place of death.

The most important reasons for granting a euthanasia request in 2013 were the patient's request (88.3% [95%CI, 82.5-92.4]), physical and/or mental suffering (87.1% [95%CI, 81.7-91.1]) and the lack of prospects for improvement (77.7% [95%CI, 71.6-82.8]) (Table 4.3).

Table 4.3 Most important reasons physicians granted and denied euthanasia requests in Flanders, Belgium, 2007 vs 2013

	2007 % (95% CI) ^a	2013 % (95% CI) ^a	Biv. p-value ^e
Most important reasons for granting the request^b	n=137	n=343	
Patient's request	93.4 (87.2-96.7)	88.3 (82.5-92.4)	.36
Physical and/or mental suffering	91.2 (85.7-94.7)	87.1 (81.7-91.1)	.51
No prospect of improvement	83.9 (76.6-89.2)	77.7 (71.6-82.8)	.29
Expected further suffering	55.2 (46.3-63.8)	48.3 (41.5-55.2)	.39
Low expected quality of life	55.2 (44.0-66.0)	45.1 (38.4-52.1)	.20
Loss of dignity	49.9 (41.0-58.8)	52.1 (35.5-49.0)	.31
Life not to be prolonged needlessly	40.8 (30.252.3)	30.7 (24.6-37.5)	.17
Tiredness of life ^c	-	25.3 (19.8-31.6)	-
Family's request	26.5 (17.5-37.9)	23.4 (18.0-29.8)	.62
Situation unbearable for family	17.6 (11.9-25.2)	13.8 (9.6-19.4)	.55
Other reasons	0	0.4 (0.1-2.6)	>.99
Most important reasons for not granting the request^b	n=85	n=66	
Patient died before decision	44.3 (31.0-58.5)	58.5 (44.8-71.0)	.16
Patient revoked request	15.6 (8.0-28.1)	17.9 (9.9-30.2)	>.99
Legal criteria were not met	21.1 (13.3-31.9)	19.6 (10.8-33.0)	>.99
Suffering was not unbearable	9.0 (4.3-17.8)	12.6 (5.6-25.9)	.54
Patient was not terminally ill ^d	1.5 (0.2-9.9)	7.5 (2.5-20.7)	.33
No well-considered request	10.4 (4.9-20.9)	10.1 (4.2-22.2)	.40
Condition was not without prospect	5.8 (2.3-13.7)	4.8 (1.2-17.4)	>.99
No voluntary request	1.3 (0.3-5.2)	0.0	>.99
Reasons external to the patient	23.4 (12.7-39.0)	2.0 (0.3-13.0)	.003
Institutional policy	6.0 (1.7-18.7)	2.0 (0.3-13.0)	.62
Personal objections	10.2 (3.8-24.6)	0.0	.03
Fear for legal consequences	7.2 (1.4-28.9)	0.0	.12
Other reasons	10.0 (5.3-18.1)	15.1 (7.1-29.2)	.56

^a Weighted percentages.

^b More than one answer could be given by the physician.

^c Tiredness of life was not included in the 2007 questionnaire.

^d Terminal status is not a formal/legal prerequisite for euthanasia, but is sometimes viewed as such by Belgian physicians.

^e Bivariate *P* Value based on Fisher's Exact Test.

When a request did not result in euthanasia in 2013 this was in 58.5% (95%CI, 44.8-71.0) of cases because the patient died before the request was granted and

in 17.9% (95%CI, 9.9-30.2) because the patient revoked the request. In 19.6% (95%CI, 10.8-33.0) the physician considered the legal criteria for due care not to have been met. In 2.0% of cases (95%CI, 0.3-13.0) the reason for not granting the request was the policy of the institutional setting where the patient died. The proportion of deaths where the physician did not grant the request for reasons external to the patient, such as institutional policy, the physician's own objections or fear of legal consequences, decreased significantly from 23.4% (95%CI, 12.7-39.0) in 2007 to 2.0% (95% CI, 0.3-13.0) in 2013 ($p=.003$). Physicians not granting a request because of personal objections decreased significantly from 10.2% (95%CI, 3.8-24.6) to 0% ($p=.03$) and where fear of legal consequences was a reason for 7.2% (95%CI, 1.4-28.9) of non-granted euthanasia requests in 2007 this was reduced to none in 2013.

4. Discussion

This study is the first in Belgium to provide nationwide population-based information on euthanasia requests, the granting of these requests and the most important reasons for granting and not granting a request from a physician's perspective. The substantial rise in performed euthanasia between 2007 and 2013 can be attributed both to increasing numbers of euthanasia requests and to increasing granting rates. These shifts are particularly evident in patients aged 80 or older, women and nursing home residents. However, cancer patients, those dying at home, those younger than 80 years and the highly educated continue to have the highest rates of requests and granting. Reasons for granting requests most mentioned by physicians were autonomy of the patient, physical and/or mental suffering and lack of prospect of improvement. Reasons external to the patient, such as institutional policy and personal objections, were substantially less often a reason for not granting a request in 2013 than in 2007.

The legislation legalizing and regulating euthanasia in 2002 created a context of increasing openness about euthanasia and end-of-life care in which patients could discuss more freely their wishes regarding their end-of-life options.¹⁰ The striking increase in the number of euthanasia requests across all patient groups between 2007 and 2013 can be linked to a continuing attitudinal and cultural shift in the population at large, where acceptance of euthanasia continues to grow strongly and values of autonomy and self-determination are increasing in importance.⁴ An increased proportion of those dying in 2013, compared with 2007, were highly

educated, something which has been associated with more empowerment, fewer communication barriers and thus perhaps the ability to frame more articulate requests.²³ There is also an indication of a certain degree of societal normalization of euthanasia, which has received heightened attention in the media in recent years, including controversial cases, leading to a more open discussion and contributing to a discourse in which euthanasia is accepted as a possible pathway to a dignified death.²⁴

Physicians, being part of overall society, probably share the overarching societal perspective, which may increase their willingness to grant euthanasia requests and may also partly explain the observed rise in granting rates. More than three quarters of dying people who explicitly expressed a euthanasia request had that request granted in 2013 compared with about half in 2007. Notable is that the increase in granted requests has also been seen in groups with traditionally relatively low numbers of requests and low chances of having their requests granted such as non-cancer patients, older people and nursing home residents¹⁰. These patient groups, in which euthanasia requests and performance are still relatively uncommon, have now come close to having the same granting rates as cancer patients.

Growing familiarity with the practice, reassurance of non-prosecution when legal criteria are met, the perception of euthanasia as part of a palliative care continuum - formally expressed in a position statement of the Flemish Federation for Palliative Care²⁵ - and diminishing reluctance in certain health care institutions, particularly those with Catholic affiliation²⁶⁻²⁸, may further account for these observations. These explanations are supported by our data; we observed a significant decrease in factors external to the patient as reasons for refusing a euthanasia request. During the first years after legalization physicians may have been more hesitant to grant and perform euthanasia. Where physicians in 2007 still rejected requests out of fear of legal consequences and because of personal objections, this was no longer the case in 2013. Further, only one request was not granted because of institutional policy in 2013.

Both in 2007 and in 2013 patient autonomy, severe physical and/or mental suffering and lack of prospects of improvement, all requirements for eligibility according to the Belgian euthanasia law, were most often cited as the most important reasons for physicians to grant a euthanasia request. These are similar to the results in the Netherlands where the most frequently mentioned reasons for granting euthanasia are no prospect of improvement, autonomy of the patient, severe symptoms other than pain and loss of dignity.¹⁶ Tiredness of life

was for the first time surveyed in 2013 as a possible reason for granting euthanasia. Some have argued in Belgium and the Netherlands for allowing euthanasia for the oldest age group who are without a serious medical condition but nonetheless tired of life. Though indicated as an important reason for granting the request in one out of four cases of euthanasia, it was never indicated as the sole reason and mostly accompanied severe suffering. This indicates that though physicians often take existential suffering into account in their decision to grant a euthanasia request, they adhere to the legal requirement of a serious condition and accompanying (physical) suffering.

Although our study uses a robust population-based sampling method, a number of study limitations have to be taken into account. While a fairly high response rate for physician surveys was achieved, we cannot exclude non-response bias. Yet analysis of non-response questionnaires revealed lack of time as the most frequent reason for non-participation. Recall bias may have influenced results, even though physicians received the questionnaire no later than eight weeks after their patient's death. The sensitivity of the survey topic may have introduced the possibility of untruthful or socially desirable reporting, but this is likely to be negligible given the explicit guarantee of anonymity and the use of descriptive terms instead of 'euthanasia'. Since this study only included deceased patients, our results might not provide a truthful picture of granting rates for decedents diagnosed with non-terminal disease.

5. Conclusion

In Flanders, Belgium euthanasia is increasingly considered as an option at the end of life. The number of requests expressed and granted increased across various patient groups, including those where requests were formerly less prevalent. However, patient groups with traditionally higher numbers of requests continue to have the highest granting rates. Following 11 years of experience with the practice, physicians are more willing to grant these requests and they refuse requests because of their own personal objections or restrictive institutional policies much less often.

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Chapter 5

Drugs used for euthanasia: a repeated population-based mortality follow-back study in Flanders, Belgium, 1998 – 2013

Sigrid Dierickx, Joachim Cohen, Robert Vander Stichele, Luc Deliens, Kenneth
Chambaere

Submitted

Abstract

Context – According to guideline recommendations, barbiturates and neuromuscular relaxants are the recommended drugs for euthanasia.

Objectives – To describe changes over time in drugs used to perform euthanasia and differences in case characteristics according to the drugs used.

Methods – Repeated population-based mortality follow-back study among physicians attending a large representative sample of deaths in 1998, 2007 and 2013 in Flanders, Belgium.

Results – In 1998 we identified 25 euthanasia cases (1.2% of all deaths), 142 cases in 2007 (2.0% of all deaths), and 349 cases in 2013 (4.6% of all deaths). Use of recommended drugs to perform euthanasia increased from 11.9% of euthanasia cases in 1998 to 55.3% in 2007 and 66.8% in 2013 ($P < .001$). In 2013, cases with recommended drugs compared to non-recommended drugs more often involved requests expressed both orally and in writing (86.8%/14.1%, $P < .001$), consultation with colleague physicians (93.8%/69.1%, $P < .001$), and administration in the presence of another physician (98.3%/54.3%, $P < .001$), and were more often self-labelled by physicians as euthanasia (95.5%/0.9%, $P < .001$) and reported to the euthanasia review committee (92.3%/3.8%, $P < .001$). Between 2007 and 2013, physicians consistently labelled cases in which non-recommended drugs were used as palliative sedation (72.8%/78.4%, $P = .791$) or alleviation of pain and symptoms (13.2%/15.0%, $P > .999$).

Conclusion – Physicians in Flanders are increasingly using the recommended drugs for euthanasia. This suggests that guidelines and training regarding the conduct and pharmacological aspects of euthanasia have had important effects on the practice of euthanasia. However, the declining but persisting use of non-recommended drugs requires further attention.

1. Introduction

In 2002 euthanasia, i.e. termination of life by a physician at the patient's explicit request, became a legal possibility at the end of life in Belgium.¹ Strict due care and procedural criteria are specified in the law to regulate the practice. The Belgian euthanasia law states that euthanasia should be performed by a physician.¹ It does not specify which drugs physicians should use to end the patient's life as therapeutic freedom is strongly defended by the medical professional associations. The Belgian professional association for pharmacists has clarified which products and materials are needed to perform euthanasia.² The recommended procedure is to administer a barbiturate overdose, optionally followed by a neuromuscular relaxant to induce respiratory arrest.² Optionally, the physician can administer a benzodiazepine (midazolam) to induce sleep before administering the barbiturate. The Belgian guideline is broadly similar to the Dutch guideline issued by the Royal Dutch Medical Association.³ However, the Dutch guideline states that a neuromuscular relaxant should always be administered, even if the patient seems to be deceased after administering the barbiturate. Other drugs such as opioids and benzodiazepines or combinations of these drugs without the use of a barbiturate and/or a neuromuscular relaxant are explicitly advised against in the Dutch guideline, because of the uncertain lethal effect and adverse side effects.^{3,4} Barbiturates are also the preferred drugs in Switzerland and some US states where physician-assisted suicide is legal.^{5,6} In Canada, the most common protocol for euthanasia is midazolam followed by propofol and a neuromuscular relaxant.⁷

The Belgian professional association for pharmacists has additionally provided instructions on the equipment needed to perform euthanasia by infusion or injection.² Information and best practices regarding the euthanasia procedure, including its performance, are also disseminated by the Life's End Information Forum (LEIF) in Flanders, the northern Dutch-speaking part of Belgium. This forum was established in the year following the enactment of the Belgian Euthanasia Law in September 2002.⁸ LEIF is a consultation service which aims to inform, assist and train physicians in end-of-life care and specifically euthanasia.^{8,9}

Once the physician has assessed all due care criteria and is convinced that euthanasia can be granted for the competent patient, it is important that the correct drugs to perform euthanasia are chosen. Failure to do so may lead to traumatic situations such as an extended time to death or awakening of the patient^{10,11}, causing distress for the patient and the attending family and health

care providers. Previous studies have shown that drugs that are advised against, i.e. opioids and sedatives, are used to perform euthanasia^{12,13} and that these drugs are used in some euthanasia cases that remain unreported to the euthanasia review committee¹².

The present study reports on the drugs used for euthanasia in Flanders, Belgium. The aims of this study are 1) to describe which drugs are used to perform euthanasia, and how this has changed since before the euthanasia law, 2) to describe euthanasia case characteristics (decision-making and administrative characteristics, physicians' perceptions of their act and reporting) in relation to the types of drugs used to perform euthanasia and 3) to describe time trends in euthanasia case characteristics in relation to drugs used to perform euthanasia.

2. Methods

2.1. Study design

We compare data from large-scale population-based mortality follow-back surveys on medical end-of-life decision-making conducted in Flanders (the Dutch-speaking northern half of Belgium) in 1998, 2007 and 2013, i.e. respectively 4 years before, 5 years after and 11 years after the introduction of euthanasia legislation in Belgium. All studies are based on a large and representative sample of deaths using the same sampling and data collection method. The Flemish Agency for Care and Health selected a random stratified sample of all death certificates of people aged one year or older within the study period. Attending physicians for these death certificates were requested to complete a questionnaire by mail about the end-of-life care and decision-making whilst consulting the patient's medical file. To guarantee absolute anonymity for participating physicians, a lawyer served as an intermediary between responding physicians, researchers and the Flemish Agency for Care and Health. The Ethical Review Board of the University Hospital of the Vrije Universiteit Brussel (VUB), the Belgian National Disciplinary Board of Physicians, and the Belgian Privacy Commission approved the mailing and anonymity procedure. The study design, sampling, and mailing procedure are described in detail elsewhere.¹⁴⁻¹⁷

A similar study was also performed in 2001, during a period in which the euthanasia debate reached its culmination point, eventually leading to the legalisation of euthanasia in 2002.¹⁸ Because of the potential bias related to

conducting the study during the euthanasia legalisation process, such as socially desirable answers, and the limited number of euthanasia cases (n=18), data for 2001 are not included in the analyses.

2.2. Questionnaire

The questionnaire first asked whether the death of the patient had been sudden and unexpected. If the answer was negative, physicians were asked about the medical decisions made at the end of the patient's life with a possible or certain life-shortening effect. We identified cases as euthanasia if the physician gave an affirmative answer to the following questions: 1) was the death the consequence of the use of drugs prescribed, supplied or administered by you or another physician with the explicit intention of hastening the end of life or of enabling the patient to end his or her own life? 2) Was the decision made at the explicit request of the patient?

In the 1998 questionnaire, physicians were asked to specify in writing which drugs were used. In 2007 and 2013, physicians were asked to indicate pre-structured response categories, which were 1) neuromuscular relaxant (curare or similar drug), 2) barbiturate, 3) benzodiazepine, 4) morphine or other opioid, and 5) other drug, with the possibility to specify the other drug in writing. Multiple answers were possible for this question. Physicians were also asked to indicate who administered the drugs by multiple choice, i.e. 1) the patient, 2) you or another physician, 3) a nurse, and 4) someone else, with the possibility to specify in writing. For this question also, multiple answers were possible.

In addition, we asked for the estimated time by which the patient's life was shortened, the manner in which the patient expressed the euthanasia request, whether the decision was discussed with others, how they would label the end-of-life act, whether they reported the act to the euthanasia review committee, and, if not reported to the committee, the reason(s) for not reporting.

2.3. Statistical analysis

Data were weighted to correct for the disproportionate stratification of deaths and adjusted to be representative of all deaths in the period covered by the surveys in terms of age, sex, marital status, province of death, cause of death, and place of death.

We dichotomized the categories in which drugs used to perform euthanasia were categorized, reflecting the recommended drugs to perform euthanasia according to the guideline of the Belgian professional association for pharmacists.² The first category, ‘recommended drugs’, includes barbiturates and neuromuscular relaxants, barbiturates used alone or with other drugs (excl. neuromuscular relaxants), and neuromuscular relaxants used alone or with other drugs (excl. barbiturates). The second category, ‘non-recommended drugs’, includes benzodiazepines and opioids, benzodiazepines used alone or with other drugs (excl. barbiturates, neuromuscular relaxants or opioids), opioids used alone or with other drugs (excl. barbiturates, neuromuscular relaxants or benzodiazepines), and other drugs.

Physician-assisted suicide, i.e. when patients administer the lethal drugs themselves, is treated as a form of euthanasia by the Belgian euthanasia review committee, although it is not mentioned in the euthanasia law. Cases of physician-assisted suicide are subject to the same due care criteria as cases of euthanasia. Therefore, cases of physician-assisted suicide were included in the analysis as cases of euthanasia.

We carried out Pearson’s chi-squared tests and Fisher exact tests to analyse differences between recommended and non-recommended drugs in euthanasia case characteristics. We also carried out Pearson’s chi-squared tests and Fisher exact tests to identify trends in the nature of drugs used to perform euthanasia.

3. Results

In 1998 we identified 25 euthanasia cases (1.2% of all deaths), in 2007 we identified 142 cases (2.0% of all deaths), and in 2013 we identified 349 cases (4.6% of all deaths) in Flanders, Belgium (Table 5.1).

Type of drugs used to perform euthanasia and time trends

The use of recommended drugs increased from 11.9% in 1998 to 55.3% in 2007 and 66.8% in 2013 ($P < 0.001$) (Table 5.2). Barbiturates combined with neuromuscular relaxants were the recommended drugs most often used in 2013 (39.7%). Non-recommended drugs were decreasingly used, from 88.1% of all cases in 1998 to 44.7% in 2007 and 33.2% in 2013. Opioids only or with other drugs (excl. barbiturate, neuromuscular relaxant or benzodiazepine) were the most often used non-recommended drugs in 2013 (16.0%).

Table 5.1 Characteristics of deaths by euthanasia in Flanders, Belgium 1998-2007-2013

	1998	2007	2013
Total number of deaths (unweighted)	1925	3623	3751
Number of euthanasia deaths (unweighted) ^b	25	142	349
Percentage of all euthanasia deaths (weighted)	1.2	2.0	4.6
Sex			
Male	40.4	61.3	51.0
Female	59.6	38.7	49.0
Age (in years)			
18-64	35.8	37.0	18.9
65-79	29.0	42.6	37.8
80 or older	35.2	20.4	43.2
Cause of death			
Cardiovascular disease ^a	14.1	3.8	14.3
Malignancies	46.1	80.2	57.4
Respiratory disease	11.1	4.7	4.1
Disease of the nervous system	7.6	7.2	7.4
Other disease	21.1	4.0	16.9
Place of death			
At home	48.4	43.1	41.8
Hospital	43.1	51.3	42.5
Care home	8.6	5.6	15.6
Other	0.0	0.0	0.1

Weighted row percentages.

^aIncludes cerebrovascular disease.

^bNumbers include 3 cases of physician-assisted suicide in 1998, 5 cases in 2007 and 6 cases in 2013. Physician-assisted suicide, i.e. when patients administer the lethal drugs themselves, is treated as a form of euthanasia by the Belgian euthanasia review committee, although it is not mentioned in the euthanasia law.

Table 5.2 Trends in drugs used to perform euthanasia 1998-2007-2013

	1998	2007	2013	<i>P</i> value ^a
Unweighted number of cases	25	142	349	
Recommended drugs ^{2,3}				
Barbiturates and neuromuscular relaxants	4.8	30.1	39.7	.009
Barbiturates only or with other drugs (excl. neuromuscular relaxants)	7.1	15.4	20.1	.258
Neuromuscular relaxants only or with other drugs (excl. barbiturates)	0.0	9.8	7.1	^b
Non-recommended drugs ³				
Benzodiazepines and opioids	17.5	20.9	14.8	.469
Benzodiazepines only or with other drugs (excl. barbiturate, neuromuscular relaxant or opioid)	9.6	0.5	1.8	^b
Opioids only or with other drugs (excl. barbiturate, neuromuscular relaxant or benzodiazepine)	61.1	23.3	16.0	<.001
Other	0.0	0.0	0.5	^b

Weighted column percentages. Missing values: 1998: n=5, 2007: n=2, 2013: n=11.

^a*P* values calculated with Pearson's chi-squared test.

^b*P* value could not be calculated because of low cell frequencies.

Chapter 5

Table 5.3 Decision-making and administration characteristics, labelling and reporting of euthanasia cases in relation to drugs used to perform euthanasia, 2013

	All cases	Drugs used to perform euthanasia		
		RD	NRD	<i>P</i> value ^a
Unweighted number of cases	349	272	64	
Type of request				
Only oral	30.5	5.7	80.5	<.001
Only in writing	1.2	1.9	0.0	.549
Oral and in writing	62.8	86.8	14.1	<.001
Advance euthanasia directive	5.5	5.7	5.4	>.999
Decision discussed with others ^b				
Another physician	85.6	93.8	69.1	<.001
Caregiver specialised in palliative care	52.4	53.5	50.3	.743
Nursing staff	54.9	54.8	52.9	.869
Relative	81.3	80.9	81.8	>.999
Person who administered the drugs				
Only physician	71.4	93.7	25.2	<.001
Only nurse	14.7	1.4	41.5	<.001
Physician and other person(s) ^c	12.4	4.5	29.0	<.001
Nurse and other person(s) (excl. physician) ^d	0.6	0.0	2.0	.327
Only other person(s) ^e	0.9	0.2	2.2	.327
Physician present during administration	83.7	98.3	54.3	<.001
Estimated degree of life-shortening				
Probably none	1.7	0.6	3.6	.261
Less than 24h	12.5	8.3	21.1	.024
1-7 days	41.0	33.3	58.6	.003
More than 1 week	44.8	57.8	16.7	<.001
Label given by the physician				
Euthanasia	64.6	95.5	0.9	<.001
Palliative or terminal sedation	28.5	4.3	78.4	<.001
Alleviation of pain and symptoms	4.9	0.0	15.0	<.001
Compassionate life-ending	0.8	0.1	2.2	.337
Other	1.2	0.1	3.5	.110
Reporting to the Euthanasia Review Committee				
Reported	63.5	92.3	3.8	<.001
Not reported because ^b				
Not euthanasia according to the physician	30.8	3.8	93.6	.001
Administrative burden	1.9	1.7	2.5	.052
Matter between physician and patient	1.7	1.6	2.1	.052
Possibly not all legal criteria adhered to	0.0	0.0	0.0	>.999
Possible judicial consequences	1.1	0.6	2.5	.272

Percentages are weighted column percentages. Missing values for drugs used to perform euthanasia: n=13. Abbreviations: RD = recommended drugs (barbiturates and/or neuromuscular relaxants); NRD= non-recommended drugs (opioids, benzodiazepines, or other drugs other than barbiturates or neuromuscular relaxants)

^a*P* values calculated with Fisher exact test.

^bMultiple answers possible

^cOther persons were a nurse and/or the patient.

^dOther persons were a palliative care team

^eOther persons were the patient with or without a palliative care team

Decision-making and administration characteristics, estimated degree of life-shortening, labelling and reporting of euthanasia cases according to the type of drugs used to perform euthanasia in 2013

Where recommended drugs were used, compared to cases where non-recommended drugs were used, the request for euthanasia was more often expressed both orally and in writing (86.8% / 14.1%, $P<.001$) and less often only orally (5.7% / 80.5%, $P<.001$) (Table 5.3). There was more often discussion with a fellow physician when recommended drugs were used (93.8% / 69.1%, $P<.001$). Recommended drugs were more often administered by a physician only (93.7% / 25.2%, $P<.001$) and less often by a nurse only (1.5% / 41.5%, $P<.001$). A physician was more often present during the administration of recommended drugs (98.3% / 54.3%, $P<.001$). If recommended drugs were used, the estimated degree of life-shortening was less often 24 hours or less (8.3% / 21.1%, $P=.024$) or one to seven days (33.3% / 58.6%, $P=.003$) and physicians more often estimated that the patient's life was shortened by more than 1 week (57.8 / 16.7%, $P<.001$) (Table 3). In cases with recommended drugs, the physician more often labelled the act as euthanasia (95.5% / 0.9%, $P<.001$), and less often as palliative sedation (4.3% / 78.4%, $P<.001$) or alleviation of pain and symptoms (0.0% / 15.0%, $P<.001$). Euthanasia cases were more frequently reported to the Federal Control and Evaluation Committee when recommended drugs were used (92.3% / 3.8%, $P<.001$).

Trends in decision-making and administration characteristics, estimated degree of life-shortening, labelling and reporting of euthanasia cases according to the type of drugs used between 1998, 2007 and 2013

Where recommended drugs were used, in 2013 compared to 2007, euthanasia requests were increasingly expressed both orally and in writing (from 66.9% in 2007 to 86.8% in 2013, $P=0.026$) and decreasingly only orally (from 24.4% in 2007 to 5.7% in 2013, $P=0.003$) (Table 5.4). Presence of a physician during administration of the drugs remained consistent (99.0% in 2007 / 98.3% in 2013, $P>.999$) as well as reporting to the Euthanasia Review Committee (92.0% in 2007 / 92.3% in 2013, $P>.999$).

Table 5.4 Trends in decision-making and administration characteristics, labelling and reporting of euthanasia cases in relation to drugs used to perform euthanasia, 1998-2007-2013

	All cases				Recommended drugs ^a				Non-recommended drugs ^b			
	1998	2007	2013	P value ^d	1998	2007	2013	P value ^d	1998	2007	2013	P value ^d
Unweighted number of cases	25	142	349		2	87	272		18	53	64	
Type of request												
Only oral	c	50.1	30.5	.005	c	24.4	5.7	.003	c	84.2	80.5	.779
Only in writing	c	6.4	1.2	.025	c	8.7	1.9	.109	c	3.8	0.0	.356
Oral and in writing	c	43.1	62.8	.010	c	66.9	86.8	.026	c	11.0	14.1	.739
Advance euthanasia directive	c	0.5	5.5	.061	c	0.0	5.7	.339	c	1.1	5.4	.550
Decision discussed with others ^f												
Another physician	48.9	77.8	85.6	<.001	100	97.4	93.8	.680	60.5	52.5	69.1	.109
Caregiver specialised in palliative care	c	50.0	52.4	.779	c	65.1	53.5	.190	c	31.3	50.3	.121
Nursing staff	30.9	54.1	54.9	.085	59.8	54	54.8	>.999	38.7	54.5	52.9	>.999
Relative	61.6	77.4	81.3	.106	100	78.9	80.9	>.999	79.7	76.8	81.8	.587
Person who administered the drugs												
Only physician	54.6	69.2	71.4	.248	100	94.5	93.7	>.999	64.8	37.3	25.2	.213
Only nurse	6.7	19.1	14.7	.459	0.0	0.0	1.4	>.999	10.1	43.1	41.5	>.999
Physician and other person(s) ^g	14.0	10.6	12.4	.888	0.0	4.5	4.5	>.999	21.1	18.5	29	.444
Nurse and other person(s) (excl. physician) ^h	0.0	0.0	0.6	-	0.0	0.0	0.0	>.999	0.0	0.0	2.0	>.999
Only other person(s) ⁱ	24.8 ^e	1.0	0.9	<.001	0.0	1	0.2	>.999	4.0	1.1	2.2	>.999
Physician present during administration	68.6	80.1	83.7	.254	100	99	98.3	>.999	85.9	55.8	54.3	>.999
Estimated degree of life-shortening												
Probably none	3.6	1.7	1.7	.684	0.0	0.0	0.6	>.999	5.4	3.8	3.6	>.999
Less than 24h	18.3	9.7	12.5	.679	0.0	4.0	8.3	.452	23.3	17.1	21.1	.585
1-7 days	60.1	44.1	41.0	.265	0.0	36.3	33.3	.689	57.5	55.4	58.6	.823
More than 1 week	18.0	44.5	44.8	.029	100	59.7	57.8	>.999	13.7	23.6	16.7	.567
Label given by the physician												
Euthanasia	c	54.3	64.6	.192	c	92.6	95.5	>.999	c	4.7	0.9	.356
Palliative or terminal sedation	c	34.1	28.5	.443	c	4.1	4.3	>.999	c	72.8	78.4	.791
Alleviation of pain and symptoms	c	6.1	4.9	.750	c	0.5	0.0	>.999	c	13.2	15.0	>.999
Compassionate life-ending	c	0.4	0.8	>.999	c	0.8	0.1	>.999	c	0.0	2.2	>.999
Other	c	5.1	1.2	.062	c	2.0	0.1	.253	c	9.3	3.5	.343

Table 5.4 Trends in decision-making and administration characteristics, labelling and reporting of euthanasia cases in relation to drugs used to perform euthanasia, 1998-2007-2013
(continued)

Reporting to the Euthanasia Review Committee	c	53.7	63.5	.194	c	92	92.3	>.999	c	4.5	3.8	>.999
Reported												
Not reported because ^f												
Not euthanasia according to the physician	c	36.1	30.8	.189	c	1.1	3.8	.236	c	83.5	93.6	.135
Administrative burden	c	9.5	1.9	.030	c	4	1.7	.547	c	17	2.5	.025
Matter between physician and patient	c	5.2	1.7	.241	c	3.9	1.6	>.999	c	7.1	2.1	.552
Possibly not all legal criteria adhered to	c	6.1	0.0	.014	c	6.3	0.0	.055	c	6.2	0.0	.136
Possible judicial consequences	c	2.1	1.1	>.999	c	1	0.6	>.999	c	3.8	2.5	>.999

Percentages are weighted column percentages. Missing values for drugs used to perform euthanasia: 1998: n=5, 2007: n=2, 2013: n=11.

^aRecommended drugs: barbiturates and/or neuromuscular relaxants

^bNon-recommended drugs: opioids, benzodiazepines, or other drugs other than barbiturates or neuromuscular relaxants

^cData for 1998 are not available as these questions were not included in the survey.

^dP values calculated with Fisher exact test (type of request, label given by physician, reporting to the Euthanasia Review Committee) or Pearson's chi-squared test (decision discussed with others, person who administered the drugs, physician present during administration, estimated degree of life-shortening).

^eThese are 4 cases in which the palliative care team and 1 case in which the patient administered the drugs.

^fMultiple answers possible

^gOther persons were a nurse, the patient and/or the patient's relative.

^hOther persons were a palliative team

ⁱOther persons were a palliative care team and/or the patient

Where non-recommended drugs were used, administrative burden (having to report the euthanasia case to the Euthanasia Review Committee) was decreasingly indicated as a reason not to report the case to the committee (from 17.0% in 2007 to 2.5% in 2013, $P=0.025$). Physicians consistently labelled cases in which non-recommended drugs were used as palliative sedation (72.8% in 2007 / 78.4% in 2013, $P=.791$) or alleviation of pain and symptoms (13.2% in 2007 / 15.0% in 2013, $P>.999$). Presence of a physician during administration of the drugs remained stable (55.8% in 2007 / 54.3% in 2013, $P>.999$) as well as reporting to the Euthanasia Review Committee (4.5% in 2007 / 3.8% in 2013, $P>.999$).

4. Discussion

Main findings

This study found that the recommended drugs, i.e. barbiturates and/or neuromuscular relaxants, were increasingly used to perform euthanasia, from 11.9% of euthanasia cases in 1998 to 55.3% in 2007 and 66.8% in 2013. The use of non-recommended drugs, especially opioids and/or benzodiazepines, decreased from 88.1% in 1998 to 44.7% in 2007 and 33.2% in 2013. Cases where the recommended drugs were used more often involved a request that was expressed both orally and in writing, consultation with colleague physicians, and administration in the presence of a physician, and were more often self-labelled by physicians as euthanasia and reported to the Euthanasia Review Committee.

Strengths and weaknesses of this study

By taking a population-based approach, we are able to report representative data on euthanasia case characteristics across care settings and diagnoses. Additionally, by repeatedly using a similar study design, sampling and mailing procedure, we can make reliable comparisons over time. However, our study also has some limitations. The study does not allow an in-depth analysis of the drugs that were administered, e.g. information on drug doses was not gathered in all the years studied. Furthermore, as we used a retrospective survey study design, recall bias cannot be excluded. Physicians were however asked to consult the patient's medical file while completing the questionnaire to reduce recall bias. The sensitivity of the survey topic may have introduced the possibility of

untruthful or socially desirable reporting, but this is likely negligible given the explicit guarantee of anonymity and the avoidance of the term ‘euthanasia’ in the survey itself. Lastly, as the 1998 sample included a small number of euthanasia cases, the possibility of type II errors, i.e. false negatives, cannot be excluded.

Meaning of the findings and comparison with other studies

We found that the recommended drugs for performing euthanasia, i.e. barbiturates and/or neuromuscular relaxants, were increasingly used after the introduction of euthanasia legislation in 2002. Before euthanasia legislation, drugs that are considered unsuitable for euthanasia and that are therefore advised against, especially morphine, were used in a majority of cases. After legalization of euthanasia, recommended drugs, i.e. barbiturates and/or neuromuscular relaxants, were increasingly used. Numbers from the Federal Control and Evaluation Committee for Euthanasia on reported cases show the same trend of recommended drugs being increasingly used to perform euthanasia.^{19,20} This suggests that since the introduction of euthanasia legislation, Flemish physicians have become increasingly familiar with recommended euthanasia procedure. Dissemination to physicians of best practices for euthanasia, for instance by the Life’s End Information Forum (LEIF)⁸, and providing training and information to clinicians through media dissemination and exchanges of experiences among professionals in a context that is increasingly open to the topic of euthanasia may have played a significant role in the increase in adoption of the guidelines. Population-based studies in the Netherlands, where euthanasia was also legalized in 2002, have also found that the recommended drugs for euthanasia are increasingly used and that most cases of euthanasia are undertaken with barbiturates and/or neuromuscular relaxants.^{21,22} Recommended drugs are however more frequently used in the Netherlands (in 80% of euthanasia or physician-assisted suicide cases in 2010²¹) than in Flanders, Belgium. This may be related to a longer experience and open societal and medical debate about good euthanasia practice, going back to as early as 1987 when the first guideline on the medico-technical aspects of euthanasia was issued in the Netherlands, before the practice was formally legalized.³

Despite the observed decrease in non-recommended drugs to perform euthanasia, one third of cases identified in this study in 2013 still involved the use of non-recommended drugs, mainly opioids or benzodiazepines, to intentionally hasten death upon patient request. Some physicians may overestimate the actual lethal effect of these drugs in persons at the very end of life.^{4,23–25} Another

possible explanation is that some physicians use drugs that are not associated with the recommended euthanasia procedure but with palliative sedation as a strategy to reduce cognitive dissonance, i.e. the mental discomfort experienced by a person with conflicting attitudes, as some clinicians find palliative sedation emotionally less burdensome to perform than euthanasia²⁶. Also, physicians may intend to hasten death without using the established procedures that make it an obvious euthanasia case but by increasing medication for sedation or pain and symptom control in order to avoid lengthy procedures, due care requirements or the administrative burden of reporting to the review committee. In these cases the requirements for due care are significantly less often adhered to than in cases in which recommended drugs were used: there was more often only an oral request, a colleague physician was less often consulted and the euthanasia was more often carried out in the absence of a physician.

Furthermore, these cases are generally not reported to the Committee and are thus not reviewed, mainly because physicians did not consider the case as euthanasia. Studies in the Netherlands also show that non-reporting of euthanasia is strongly related to the type of drugs used.²⁷ These non-reported cases are usually considered as palliative sedation or intensified alleviation of pain and symptoms by the attending physicians. Flemish physicians seem to use a fairly narrow definition of euthanasia based on the drugs used and legal procedures. What is not performed with these drugs or is not in accordance with the legal procedures, is not euthanasia in their eyes, but rather a grey zone that they label as palliative sedation. Our findings corroborate previous studies identifying this grey zone.^{12,21,27-29} Although some framework papers make a strict distinction between euthanasia and palliative sedation in terms of physicians' intention and the outcome of the act^{30,31}, previous research showed that this distinction is not always clear in clinical practice³²⁻³⁷ and that some physicians administer sedatives with the intention of hastening death.^{38,39}

In half of all euthanasia cases in 2013, the decision to perform euthanasia had been discussed with a palliative care expert. This does not preclude the possibility that palliative care services had been involved outside of the euthanasia decision-making procedure. Previously we have found that palliative care services were involved in 71% of deaths with a euthanasia request.⁴⁰ When no palliative care services had been involved, this had been in more than half of the cases because the existing care already sufficiently addressed the patient's palliative and supportive care needs. Nevertheless, involvement of palliative care experts may increase compliance with guidelines regarding drugs for euthanasia.”

Implications and recommendations

The obsolete practice in which benzodiazepines and/or morphine are used to intentionally end a patient's life upon patient request requires adequate attention. Despite an increase in euthanasia being performed with drugs recommended by euthanasia guidelines, physicians still use drugs that are advised against, mainly opioids, to hasten death upon explicit patient request. These cases remain unreported to the Euthanasia Review Committee because physicians do not consider them to be euthanasia.

Continuation and further expansion of initiatives aimed at improving health professionals' skills regarding euthanasia performance are recommended. Further education of physicians on euthanasia procedures and the effects and side effects of opioids and sedatives is needed to avoid euthanasia being performed in a way that may be harmful to patients and their relatives, and beyond societal control. To further encourage physicians to report their cases to the Euthanasia Review Committee and to use the recommended drugs for euthanasia and thus improve quality of euthanasia performance, a strong signal is needed from the medical community, e.g. through official advice from the National Belgian Disciplinary Board of Physicians. Future studies should focus on the euthanasia practice with non-recommended drugs, physicians' motives to intentionally hasten death with non-recommended drugs and possible complications associated with non-recommended euthanasia practice.

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Chapter 6

Commonalities and differences in legal euthanasia and legal assisted suicide in three countries: a population-level comparison

Sigrid Dierickx, Joachim Cohen, Yolanda Penders, Bregje Onwuteaka-Philipsen, Agnes van der Heide, Milo A Puhan, Sarah Ziegler, Georg Bosshard, Luc Deliens, Kenneth Chambaere

Submitted

Abstract

Background – Euthanasia and assisted suicide (EAS) are legal in Belgium and the Netherlands, while only assisted suicide is legal in Switzerland. As an increasing number of countries are considering EAS legalization, it is important to describe existing practice. This study aims to describe and compare EAS practice in Flanders, Belgium (BE), the Netherlands (NL) and Switzerland (CH).

Methods – Mortality follow-back surveys among attending physicians of a random sample of death certificates. We selected all deaths by EAS for analysis.

Results – We studied 349 deaths by EAS in BE (4.6% of all deaths), 851 in NL (4.6% of all deaths) and 65 in CH (1.4% of all deaths). People who died by EAS were most commonly aged 65 or older (BE: 81%, NL: 77% and CH: 71%) and were mostly diagnosed with cancer (BE: 57% and NL: 66%). Home was the most common place of death in NL (79%), while in BE and CH more variation was found regarding to place of death. EAS requests were expressed most often both orally and in writing in BE (67%) and NL (74%), while In CH oral requests were most common (76%). Life-shortening was frequently discussed with a colleague physician and/or the patient's relatives (BE: 86% and 81% respectively, NL: 90% and 64%, CH: 60% and 75%). Life-shortening as estimated by the attending physician was most often between one and seven days in BE (41%), one to four weeks in NL (36%), and more than four weeks in CH (41%).

Conclusion – EAS practice characteristics vary considerably in the studied countries with legal EAS, even between countries with largely similar EAS legislation. This suggests that, in addition to the legal context, cultural factors as well as the manner in which legislation is implemented play a role in how EAS legislation translates into practice.

1. Introduction

Medical end-of-life decisions have become a substantial part of contemporary medical practice. These decisions increasingly include euthanasia, i.e. a physician intentionally ending a patient's life upon explicit patient request, or assisted suicide, i.e. when a physician prescribes drugs to enable a patient to end his or her life. Euthanasia or assisted suicide are currently legal in the Netherlands, Belgium, Luxembourg, Colombia and Canada. Assisted suicide, though not euthanasia, is legally possible in Switzerland and six American states (California, Colorado, Montana, Oregon, Vermont and Washington).¹ In the American state of Hawaii assisted suicide legislation will take effect in January 2019 and in the Australian province of Victoria a euthanasia law will come into force as of mid 2019.

Large-scale mortality follow-back studies on end-of-life decision-making have been conducted repeatedly in some countries, allowing the monitoring of developments in medical end-of-life practice, including euthanasia and assisted suicide (EAS).²⁻⁵ A study across six European countries conducted in 2001-2002 reported rates of EAS ranging from 0% of all deaths (Sweden) to 2.8% of all deaths (the Netherlands).² More recent studies have shown that in Belgium (Flanders) frequency of EAS was estimated in 2013 to be 4.6% of all deaths.³ In the Netherlands in 2015 this was also 4.6%.⁴ In the German-speaking part of Switzerland in 2013, EAS accounted for 1.4% of all deaths.⁵

In this study, we focus on three jurisdictions with legal euthanasia and/or assisted suicide for which there exists recent data collected using the same study design, i.e. Belgium (Flanders), the Netherlands and Switzerland (including all three Swiss language communities, i.e. German, French and Italian). Table 6.1 contains details on the assisted dying legislations in the studied countries. EAS legislation is very similar in Belgium and the Netherlands, where both euthanasia and assisted suicide are an option, with large similarities in the legal substantive and procedural requirements for EAS.⁶ In contrast, only assisted suicide and not euthanasia is legal in Switzerland. No legal framework has been created in Switzerland, rather it is tolerated within the existing criminal code which states that aiding in suicide for non-selfish motives is not punishable.

As an increasing number of countries are considering EAS legalization, it is important to describe existing practice.^{1,7} Identifying commonalities in EAS practice between countries may enable countries with new EAS legislation or legislation in the making to proactively address certain issues regarding patient

Table 6.1 Belgian, Dutch and Swiss legislation on euthanasia and assisted suicide

	Belgium	The Netherlands	Switzerland
Legal status of euthanasia	Euthanasia is permitted.	Euthanasia is permitted.	Euthanasia is not permitted.
Legal status of assisted suicide	Although assisted suicide is not mentioned in the euthanasia law, it is treated as a form of euthanasia by the euthanasia review committee as long as all due care requirements are met. ³¹	Assisted suicide is permitted.	Assisted suicide is permitted.
Year and method of legalization	2002, legislation (Act on euthanasia)	2002, legislation (Termination of life on request and assisted suicide act)	1942, penal code (Article 115)
Eligibility criteria	<ul style="list-style-type: none"> - Legally competent adult or emancipated minor - Minor with capacity of discernment (only physical suffering) 	<ul style="list-style-type: none"> - Patient is at least 12 years old and has decision-making capacity 	None specified in the law. Most right to die organisations require the patient to be an adult of sound judgement.
Due care requirements	<p>Substantive requirements:</p> <ul style="list-style-type: none"> - The patient's request must be voluntary, well-considered and repeated, and must not be the result of any external pressure. - 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 - The physician must inform the patient about his/her health condition and prospects - The physician and patient must come to the belief that there is no reasonable prospect of improvement in the patient's situation <p>Procedural requirements:</p> <ul style="list-style-type: none"> - The treating physician must consult another physician before proceeding. - The physician must notify the case of euthanasia for review to the Federal Control and Evaluation Committee Euthanasia. 	<p>Substantive requirements:</p> <ul style="list-style-type: none"> - The patient's request must be voluntary and well-considered. - The patient's suffering must be unbearable and hopeless. - The physician must inform the patient about his/her health condition and prospects. - The physician and patient must come to the belief that there is no reasonable prospect of improvement in the patient's situation - The physician must terminate life in a medically and technically appropriate way. <p>Procedural requirements:</p> <ul style="list-style-type: none"> - The treating physician must consult another physician before proceeding. - The physician must notify the case of euthanasia for review to one of five regional Euthanasia Review Committees. 	The law does not specify any due care criteria. The only requirement is that the person assisting does so without any "selfish motives", in other words in the absence of any self-interest (such as monetary gain).
Physician involvement for performance of EAS	Required.	Required.	Not required.

populations and EAS decision-making and performance. Additionally, a cross-country comparison of EAS case characteristics can shed light on the relation between EAS legislation on the one hand and the profile of people receiving EAS and clinical and decision-making characteristics on the other. If differences between countries are found, these may point to a possible impact of the way in which EAS practice is regulated and implemented on actual EAS practice.

This study aims to describe commonalities and differences in EAS characteristics in three different countries. The following research questions are addressed: 1) How do the sociodemographic characteristics of people receiving EAS differ across countries? 2) How do physician, decision-making and clinical characteristics of EAS differ between countries?

2. Methods

2.1. Study design & sample

We conducted mortality follow-back surveys in Flanders, the northern Dutch-speaking part of Belgium, from January through June 2013 (N=6871), in the Netherlands from August through November 2015 (N=9351), and in Switzerland between August 2013 and January 2014 (N=8963). This robust study method was first developed in the Netherlands in 1990 and has since then been used in several countries to study the nationwide prevalence and characteristics of medical end-of-life decisions including euthanasia and assisted suicide.²⁻⁵ A random stratified sample of all death certificates is selected. In Belgium and the Netherlands, stratification was applied based on underlying cause of death as indicated on the death certificate and the estimated corresponding likelihood of an end-of-life decision. In Switzerland a random sample was drawn without stratification based on underlying cause of death, but the French and Italian regions in Switzerland were oversampled to compensate for the smaller population size. Physicians who certified a death certificate in the samples were sent a questionnaire about the end-of-life care and decision-making that had preceded the death of the patient. If the certifying physician was not the attending physician, he or she was asked to pass the questionnaire to the attending physician. Afterwards, information from the death certificates was linked anonymously to the questionnaire data. Response rates were 61% in Belgium, 78% in the Netherlands and 59% in Switzerland (region-specific response rates

for Switzerland were: German: 64%, French: 52%, Italian: 62%). More details on study design and sample can be found elsewhere.^{3,4,8}

2.2. Questionnaire

Euthanasia and assisted suicide. The questionnaires did not ask about EAS directly. Instead, EAS cases were identified based on affirmative answers of the physician on the following questions: 1) “Was death the consequence of the use of drugs prescribed, supplied or administered by you or another physician with the explicit intention of hastening the patient’s death or of enabling the patient to end his or her own life?” and 2) “Was this decision made at the explicit request of the patient?” If the lethal drugs were administered by the patient the act was classified as assisted suicide, if not the act was classified as euthanasia.

Patient characteristics. For Belgium information regarding the patient’s sex, age, cause of death and place of death was obtained from the death certificate data and linked anonymously after data collection. For the Netherlands, the patient’s sex, age and cause of death is obtained from the death certificate while place of death is asked in the questionnaire. For Switzerland, the patient’s sex and age are obtained from the death certificate, cause of death and place of death are asked in the questionnaire.

Physician characteristics. Type of physician: whether the certifying physician was a general practitioner or a clinical specialist or elderly care physician. For Belgium and Switzerland, answer options were ‘general practitioner’ or ‘clinical specialist’. In the Netherlands, an additional option was possible, namely ‘elderly care physician’, who is not a clinical specialist working in a hospital but works in a nursing home.

Decision-making characteristics. Type of request: whether the request was expressed only orally, only in writing, or both orally and in writing. Decision discussed with others: whether the decision to perform EAS was discussed with the patient’s relatives, colleague physicians, or the nursing staff. Multiple answers were possible for this question.

Clinical characteristics. Shortening of life: physician’s estimation by how much time the patient’s life was shortened. Person who administered the lethal drugs: whether the lethal drugs were administered by a physician, a nurse, the patient, and/or another person.

2.3. Statistical analysis

Data were weighted to correct for stratified sampling and adjusted to be representative for all deaths that occurred in the sampling period.^{3,4}

We report weighted percentages and 95% confidence intervals of frequency of EAS and patient, physician, decision-making and clinical characteristics of EAS cases. Differences between countries were calculated using Pearson's Chi-square tests. Data were analysed using the SPSS Statistics 25 complex samples procedure to control for the stratified sample design (Belgium), SPSS Statistics 22 (the Netherlands) and Stata (Switzerland).

2.4. Ethics approval

For Belgium, ethics approval was obtained from the Ethical Review Board of the Brussels University Hospital of the Vrije Universiteit Brussel. In the Netherlands, ethics approval is not required for posthumous data collection of anonymous patient data. For Switzerland, the study was issued a waiver by the Zurich Cantonal Ethics Board (KEK-StV-Nr. 23/13) since the study did not fall under the regulations for human research acts.

3. Results

We studied 349 deaths by EAS in Belgium, 851 in the Netherlands and 65 in Switzerland (Table 6.2). The frequency of euthanasia was highest in Belgium (4.6% of all deaths, weighted percentage) and the Netherlands (4.5% of all deaths, weighted percentage) compared to Switzerland (0.4% of all deaths, weighted percentage) ($p < 0.001$). In Switzerland frequency of assisted suicide was highest (1.0%) in comparison with Belgium (0.05%) and the Netherlands (0.1%) ($p < 0.001$).

Table 6.2 Incidence of euthanasia and assisted suicide (EAS) in Belgium, the Netherlands and Switzerland

	Flanders, Belgium (BE) 2013		Netherlands (NL) 2015		Switzerland (CH) 2013		p-value
	n	% (95% CI)	n	% (95% CI)	n	% (95% CI)	
Total no. of sampled deaths (n)	6871		9351		8963		
Total no. of studied deaths (n)	3751		7761		5239		
Deaths by EAS	349	4.6 (4.0-5.2)	851	4.6 (4.2-5.1)	65	1.3 (1.0-1.7)	<0.001
Euthanasia	343	4.6 (4.0-5.2)	829	4.5 (4.1-5.0)	19	0.4 (0.2-0.6)	<0.001
Assisted suicide	6	0.1 (0.02-0.1)	22	0.1 (0.1-0.2)	46	1.0 (0.7-1.3)	<0.001

Unweighted n and weighted percentages. Due to the weighting procedure the percentages in the table cannot be derived from the unweighted absolute n in the table.

Patient characteristics of deaths by EAS

In Belgium and the Netherlands EAS was slightly more common among men (51% and 54% respectively) than women while the reverse was true for Switzerland (43%) ($p=0.238$) (Table 6.3). For both Belgium and Switzerland, the largest group of people receiving EAS was aged 80 or older (43% and 39% respectively) while in the Netherlands EAS was most common among people between 65 and 79 years old (42%). The most common cause of death was cancer in Belgium (57%) and the Netherlands (66%). In 69% of Swiss deaths by EAS the physician indicated suicide as cause of death. As no information was available on the underlying cause of death for these deaths, comparability with causes of death in Belgium and the Netherlands is limited. Home was the most common place of death in the Netherlands (79%) and, to a lesser extent, in Belgium (43%) but not in Switzerland (33%). Deaths by EAS occurred less frequently in the hospital setting compared to home in all three countries, i.e. the Netherlands (4%), Belgium (36%), and Switzerland (16%). In 44% of deaths by EAS in Switzerland, EAS occurred in a place other than at home, in hospital or in a long-term care facility. This other place is frequently a clinic of Swiss right to die organisations.

Table 6.3 Characteristics of people who died by EAS in Belgium, the Netherlands and Switzerland

	Flanders, Belgium (BE) 2013 (n=349)		Netherlands (NL) 2015 (n=851)		Switzerland (CH) 2013 (n=65)		p-value
	n	% (95% CI)	n	% (95% CI)	n	% (95% CI)	
Sex							0.238
Male	174	51.0 (44.2-57.7)	447	53.8 (48.6-58.9)	28	42.5 (30.7-55.3)	
Female	175	49.0 (42.3-55.8)	404	46.2 (41.1- 51.4)	37	57.5 (44.7-69.4)	
Age (in years)							0.221
18-64 ^a	73	18.9 (14.5-24.3)	219	22.8 (18.7-27.4)	17	28.7 (18.5-41.8)	
65-79	131	37.8 (31.5-44.7)	366	41.7 (36.7-46.9)	21	31.8 (21.3-44.6)	
80 or older	145	43.2 (36.8-49.9)	266	35.5 (30.7-40.7)	27	39.4 (27.9-52.3)	
Cause of death^b							0.010
Cardiovascular disease	34	14.3 (9.9-20.2)	32	4.8 (2.9-7.4)	3	10.8 (3.1-31.3)	
Cancer	211	57.4 (54.1-60.6)	605	65.9 (60.8-70.7)	14	58.2 (36.6-77.1)	
Respiratory disease	9	4.1 (1.8-8.8)	43	7.0 (4.7-10.1)	3	12.3 (3.6-34.7)	
Disease of the nervous system	26	7.4 (4.4-12.0)	78	8.7 (6.1-12.0)	2	6.0 (1.2-26.0)	
Other	69	16.9 (12.4-22.5)	93	13.5 (10.3-17.4)	3	12.6 (3.7-35.3)	
Place of death							<0.001
Hospital	73	35.7 (29.1-42.8)	23	4.3 (2.5-6.7)	11	16.2 (8.9-27.7)	
Home	197	43.1 (36.7-49.8)	705	78.5 (74.0-82.5)	22	33.4 (22.6-46.3)	
Long-term care facility	56	12.8 (9.0-17.7)	56	8.8 (6.2-12.1)	5	6.7 (2.6-16.1)	
Other	23	8.5 (5.2-13.4)	60	8.5 (5.9-11.8)	26 ^c	43.7 (31.6-56.7)	

Unweighted n and weighted column percentages. Missing cases: cause of death $n_{CH}=40$; place of death $n_{NL}=7$, $n_{CH}=1$.

a: 17-64 for NL

b: The Swiss questionnaire includes the category 'suicide' and 40 cases of assisted suicide are marked as such regardless of the underlying disease. As no information is available on the underlying cause of death for these cases, the cases were coded as missing for cause of death. Comparability with cause of death in Belgium and the Netherlands is therefore limited.

c: Other place is frequently a clinic of Swiss right to die organizations.

Physician, decision-making and clinical characteristics of deaths by EAS

The attending physician was a general practitioner in 93% of deaths by EAS in the Netherlands, in 60% in Belgium, and in 71% in Switzerland (Table 6.4).

Table 6.4 Physician, decision-making and clinical characteristics of deaths by EAS in Belgium, the Netherlands and Switzerland

	Flanders, Belgium (BE) 2013 (n=349)		Netherlands (NL) 2015 (n=851)		Switzerland (CH) ^a 2013 (n=65)		P-value
	n	% (95% CI)	n	% (95% CI)	n	% (95% CI)	
Physician characteristics							
<i>Type of physician</i>							
General practitioner	79	60.0 (52.9-66.6)	810	92.7 (89.6-95.0)	23	71.2 (51.7-85.1)	<0.001
Specialist ^b	260	40.0 (33.4-47.1)	41	7.3 (5.0-10.4)	9	28.8 (14.9-48.3)	
Decision-making characteristics							
<i>Type of request</i>							
Only oral	61	32.3 (25.8-39.5)	104	21.5 (17.4-26.0)	24	76.4 (56.5-88.9)	<0.001
Only in writing	11	1.3 (0.6-2.6)	44	4.6 (2.8-7.2)	3	10.8 (3.3-30.3)	
Oral and in writing	249	66.5 (59.2-73.0)	688	73.9 (69.1-78.3)	4	12.9 (4.5-31.6)	
<i>Life-shortening discussed with others^c</i>							
Patient's relative(s)	280	81.3 (75.3-86.1)	501	63.6 (58.5-68.5)	25	76.0 (57.1-88.3)	<0.001
Colleague physician	311	85.6 (80.1-89.8)	792	89.7 (86.2-92.6)	20	59.5 (40.7-75.8)	<0.001
Nursing staff	192	54.9 (48.0-61.6)	112	14.9 (11.5-18.9)	13	36.8 (21.3-55.6)	<0.001
Clinical characteristics							
<i>Shortening of life as estimates by the physician</i>							
Less than 24h	39	14.2 (9.9-19.9)	48	10.7 (7.7-14.2)	9	28.5 (14.9-47.6)	<0.001
1-7 days	109	41.0 (34.4-48.0)	206	25.9 (21.5-30.7)	10	26.0 (13.4-44.2)	
1-4 weeks	85	22.2 (17.1-28.2)	319	36.0 (31.1-41.2)	2	4.8 (1.1-18.7)	
More than 4 weeks	109	22.6 (17.6-28.5)	260	27.3	15	20.7 (12.7-31.8)	
<i>Person who administered the lethal drugs</i>							
Only physician	277	71.4 (64.3-77.5)	759	87.3 (83.5-90.5)	3	3.4 (1.1-10.4)	<0.001
Patient with or without another person ^d	6	1.1 (0.4-2.9)	32	3.2 (1.7-5.6)	46	73.3 (60.9-82.9)	
Physician and another person ^e (excl. patient)	27	12.2 (8.2-17.8)	16	5.0 (3.1-7.7)	2	2.7 (0.6-1.1)	
Other ^f	25	15.4 (10.5-21.9)	10	4.4 (2.6-7.0)	14	20.7 (12.2-32.8)	

Unweighted n and weighted column percentages. Missing cases: type of physician: n_{BE}=10, n_{NL}=0, n_{CH}=4; type of request n_{BE}=25, n_{NL}=15, n_{CH}=34; decision discussed with others n_{BE}=2, n_{NL}=17, n_{CH}=34; shortening of life n_{BE}=7, n_{NL}=18, n_{CH}=31; person who administered the lethal drugs n_{BE}=14, n_{NL}=34.

a: For Switzerland, in 34 EAS cases the physician filling in the questionnaire did not meet the patient before death, therefore information on the decision-making and/or clinical characteristics is missing in up to 34 cases (in some cases the physician was notified of the circumstances of death).

c: Multiple answers possible, therefore percentages do not add up to 100%.

d: Other persons were: BE: palliative team, NL: physician, CH: nurse, unspecified other person

e: Other persons were: BE: nurse, palliative team, NL: nurse, other physician, CH: nurse, unspecified other person

f: Other persons were: BE: nurse, palliative team, NL: nurse, other physician, CH: nurse, unspecified other person

In 67% of deaths by EAS the request was expressed both orally and in writing in Belgium, in 74% in the Netherlands, and in 13% in Switzerland. In Switzerland the request was most frequently expressed only orally (76%), while in Belgium 32% and in the Netherlands 22% was expressed only orally. Life-shortening was discussed with a colleague physician in Belgium in 86%, in the Netherlands in 90%, and in Switzerland in 60%. Life-shortening was also frequently discussed

with the patient's relatives in all three countries, ranging from 64% in the Netherlands to 76% in Switzerland and 81% in Belgium.

Shortening of life as estimated by the attending physician was less than 24 hours in 24% in Switzerland, 14% in Belgium and 11% in the Netherlands. Shortening of life was in 41% of EAS cases in Belgium estimated to be between one and seven days, in 26% in the Netherlands and in 26% in Switzerland. In the Netherlands shortening of life was most often estimated at one to four weeks (36%), compared to 22% in Belgium and 5% in Switzerland.

The lethal drugs were administered by only a physician in the Netherlands in 87% of deaths by EAS, in Belgium in 71% and in Switzerland in 3%. The patient, with or without another person, administered the lethal drugs in 73% of deaths by EAS in Switzerland, in 1% in Belgium and in 3% in the Netherlands. A person other than the physician or the patient administered the drugs in 15% in Belgium, in 4% in the Netherlands and in 21% in Switzerland.

4. Discussion

This population-level comparative study found a number of commonalities as well as differences in EAS practice in Belgium, the Netherlands and Switzerland. Euthanasia was more prevalent in Belgium and the Netherlands, where it is legal, than in Switzerland where only assisted suicide is legal. Similarities included that patients were most commonly aged 65 or older and were mostly diagnosed with cancer. Differences included that home was the most common place of death in the Netherlands, while in Belgium and Switzerland more variation was found regarding to place of death. Life-shortening was more frequently discussed with a colleague physician in Belgium and the Netherlands than in Switzerland.

Data were collected using a robust population-based method in all three countries that provides representative data on end-of-life care and decision-making. This method has been repeatedly applied across various countries and has proven to be a highly reliable method for studying end-of-life decisions.²⁻⁵ Due to the use of the same questions regarding end-of-life decisions in all three countries, deaths by euthanasia and assisted suicide could be identified in an identical manner in all three countries. This allows for reliable comparison of EAS practice between the studied countries. Also, strict anonymity procedures were used, precluding identification of participants or study subjects.

Some limitations should be taken into account when interpreting the study results. Due to differences in certification of causes of death between the studied countries, comparability of underlying cause of death in EAS is limited. Also, considering the sensitive topic of euthanasia and assisted suicide, socially desirable answering cannot be excluded. Use of descriptive questions instead of using the terms ‘euthanasia’ or ‘assisted suicide’ and the strict guarantee of anonymity probably may have mitigated this bias. The fact that some physicians were honest about euthanasia acts in a country where it is illegal supports this assumption. Further, as with all retrospective research, there may be recall bias. Measures were taken to limit possible recall bias. For instance, physicians were encouraged to consult the patient’s medical file when completing the questionnaire, and the time between the patient’s death and the moment of sending the questionnaire was restricted. An additional limitation is the small number of cases in the Swiss sample, which complicates between-country comparison. Lastly, information on cause of death and place of death was gathered in different ways, i.e. either through the questionnaire or obtained from the death certificate.

Our study suggests that differences in legislation are accompanied by differences in practice. In Switzerland only assisted suicide is legal and not euthanasia which explains the much higher prevalence of prevalence of assisted suicide than of euthanasia in the country. Belgium and the Netherlands have a highly similar EAS legislation⁶ with both euthanasia and assisted suicide as legal options and both countries also have a similar percentage of EAS (4.6% of all deaths). However, similar legislation does not imply similar practice. Our findings corroborate previous research identifying the importance of cultural differences for EAS practice, despite the same legislation.⁹⁻¹¹ These cultural factors include physicians’ attitudes towards the necessity of existing legal safeguards for EAS practice, physicians’ attitudes towards openly discussing and performing EAS, patients’ attitudes towards requesting EAS.

We found, foremost, a striking difference in the place where EAS is carried out. In the Netherlands, EAS is mostly performed at home by a GP while in Belgium and Switzerland the setting is more varied. Implementation of euthanasia legislation differed between Belgium and the Netherlands, with the Dutch SCEN organization focusing primarily on GP’s, whereas LEIF in Flanders also focused on hospital specialist. There also may be a tendency among Dutch clinical specialists to refer patients with a euthanasia request to their GP. Additionally, home is in general more frequently the place of death in the Netherlands

compared to Belgium and Switzerland.¹³⁻¹⁵ Also notable is that 44% of deaths by EAS in Switzerland are carried out elsewhere than the hospital, home or nursing home, as EAS in Switzerland is often carried out in the clinics of Dignitas and Exit.^{16,17}

In the countries where both euthanasia and assisted suicide are legally available, assisted suicide practice is remarkably limited: assisted suicide is more prevalent in Switzerland (1.0%) compared to Belgium (0.1%) and the Netherlands (0.1%). A Dutch study found that in 75% of the studied EAS cases euthanasia was preferred over assisted suicide.¹⁸ Several factors may explain why euthanasia is chosen over assisted suicide when both options are available. Firstly, euthanasia may be pharmacologically the preferred method as it allows more control to avoid possible complications (e.g. malabsorption of the barbiturate) and ensures a rapid death.^{18,19} Secondly, while autonomy is probably an important motive in both decisions, patients may prefer a certain medicalization of a serious and difficult act.^{18,20} Thirdly, sometimes there may be no choice between euthanasia and assisted suicide, for instance when the patient is physically or psychologically unable to administer the lethal drugs themselves.¹⁸ On the other hand, assisted suicide can be preferred over euthanasia as it is often considered to be less of a burden to the physician and lays the responsibility with the patient.¹⁸ Whatever the reason to prefer one option over the other, the ultimate decision should be in accordance with both the physicians' and the patient's personal preferences.

In the US, assisted suicide currently accounts for approximately 0.4% of deaths in Oregon²¹ and Washington State²² compared to 1% in Switzerland found in this study. Reports from Oregon and Washington show that assisted suicide is mainly used by people over 65 and is most often carried out at the patient's home.^{21,22} This may be explained by differing legal contexts. Switzerland has no legalization of the practice (i.e. created a legal framework especially for it); but rather it is tolerated within the existing criminal law. In the US, assisted suicide is mainly legalized through legislation with clear regulations such as the requirement that the patient must suffer from terminal illness.²³ Also an important factor for the difference in assisted suicide rate is likely the longer history of assisted suicide practice in Switzerland which started in the 1980s, while the first US state to legalize assisted suicide was Oregon in 1997.²⁴ The higher incidence in Switzerland may also be linked to the strong visibility of Swiss right to die organizations that are also actively involved in assisted suicide practice.¹⁷

Life shortening was more often discussed with fellow physicians in Belgium and the Netherlands than in Switzerland, which is likely due to the fact that this is not

a legal obligation in Switzerland. Also, we found that for Swiss deaths by EAS, physicians more often estimated life-shortening to be less than 24h. If the physician was of the opinion that the patient's life was probably not shortened or shortened by less than 24h, discussion of life-shortening may have been deemed needless. Differences in discussion with nursing staff are related to the place of death; as most deaths by EAS occur at home in the Netherlands, nursing staff are less frequently involved. Discussion of life-shortening with the patient's relatives ranged from 64% (Netherlands) to 81% (Belgium). Involvement of relatives in the decision-making process should be encouraged, as this may have psychosocial benefits for both patient and relatives.³⁰

In conclusion, nationwide mortality follow-back studies on end-of-life decision-making provide important insights into EAS practice by allowing reliable between-country comparison. The findings of this study suggest that, in addition to the legal context, cultural factors as well as the manner in which legislation is implemented play a role in how EAS legislation translates into practice. Further cross-country comparison of EAS practice, including jurisdictions outside of Europe, is recommended to examine how EAS practice relates to specific legal and cultural contexts and implementation of legislation, and interactions therein.

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PART III

CURRENT DEBATES REGARDING EUTHANASIA

Chapter 7

Involvement of palliative care in euthanasia practice in a context of legalized euthanasia: A population-based mortality follow-back study

Sigrid Dierickx, Luc Deliens, Joachim Cohen, Kenneth Chambaere

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Abstract

Background – In the international debate about assisted dying, it is commonly stated that euthanasia is incompatible with palliative care. In Belgium, where euthanasia was legalized in 2002, the Federation for Palliative Care Flanders has endorsed the viewpoint that euthanasia can be embedded in palliative care.

Aim – To examine the involvement of palliative care services in euthanasia practice in a context of legalized euthanasia.

Design – Population-based mortality follow-back survey.

Setting/participants – Physicians attending a random sample of 6871 deaths in Flanders, Belgium, in 2013.

Results – People requesting euthanasia were more likely to have received palliative care (70.9%) than other people dying non-suddenly (45.2%) (odds ratio = 2.1 (95% confidence interval, 1.5–2.9)). The most frequently indicated reasons for non-referral to a palliative care service in those requesting euthanasia were that existing care already sufficiently addressed the patient's palliative and supportive care needs (56.5%) and that the patient did not want to be referred (26.1%). The likelihood of a request being granted did not differ between cases with or without palliative care involvement. Palliative care professionals were involved in the decision-making process and/or performance of euthanasia in 59.8% of all euthanasia deaths; this involvement was higher in hospitals (76.0%) than at home (47.0%) or in nursing homes (49.5%).

Conclusion – In Flanders, in a context of legalized euthanasia, euthanasia and palliative care do not seem to be contradictory practices. A substantial proportion of people who make a euthanasia request are seen by palliative care services, and for a majority of these, the request is granted.

1. Introduction

Despite considerable progress made in palliative care, physicians still encounter severely ill people requesting medical assistance in dying for reasons of physical, psychological, and/or existential suffering.¹⁻⁵ Although some form of medically assisted dying is legal under certain conditions in several countries, the practice remains a heavily debated medical and societal issue. Euthanasia and physician-assisted suicide are legally possible in the Netherlands, Belgium, Luxembourg, Colombia, and Canada, while physician-assisted suicide only is legal in six American states (Oregon, Washington, Montana, Vermont, California, and Colorado).⁶ German law allows assisted suicide within certain circumstances but the specific requirements remain unclear, leaving physicians in legal uncertainty.

It is commonly stated that euthanasia and physician-assisted suicide are incompatible with good palliative care.^{7,8} The European Association for Palliative Care has, for instance, promulgated the position that euthanasia and physician-assisted suicide should not be included in palliative care practice.^{9,10} However, palliative care practice in those jurisdictions where medically assisted dying is legal is faced with questions about how people who are receiving palliative care can access medically assisted dying. In Belgium, for instance, the Federation of Palliative Care Flanders has accepted euthanasia in an official position paper, including at the end of a palliative care pathway.¹¹

The context of legalized medically assisted dying and the presumed contradiction between euthanasia and the philosophy of the palliative care approach make it highly relevant to study the actual involvement of palliative care in euthanasia practice. This study focuses on Belgium, where euthanasia has been legal under certain conditions since 2002. In the same year, a law on palliative care was passed, making it a basic patient right and formulating measures to enhance the provision of and access to palliative care services.¹² Palliative care has been indicated as well-developed in Belgium^{13,14}, with palliative care professionals active in all care facilities and palliative home care services organized in regional networks.

In Belgium, the option of euthanasia is not restricted to people with a terminal condition. People with a chronic, nonterminal disorder are also eligible for euthanasia, but these requests should adhere to the additional legal requirement of a 1-month waiting period between the euthanasia request and the performance of euthanasia.¹⁵ For people requesting euthanasia because of a terminal disorder, no waiting period is required. The Belgian euthanasia law does not include a

compulsory palliative care consultation; it does, however, require the physician to inform the patient of all available treatment options, including palliative care. The patient is not required to try palliative care as it is a patient's right to refuse treatment, including palliative care treatment.

This study examines the involvement of palliative care services in the care of people requesting euthanasia and in the decision-making and performance of euthanasia in a context of legal euthanasia in Flanders, the northern Dutch-speaking part of Belgium. Our research questions are as follows: how often are palliative care services involved in the end-of-life care of people who request euthanasia compared with others dying non-suddenly, what are the reasons for physicians not to refer a patient requesting euthanasia to a palliative care service, does the granting rate of euthanasia requests differ according to the involvement of palliative care services in end-of-life care, and what is the role of palliative care professionals in the decision-making process and performance of euthanasia requests that are granted.

2. Methods

2.1. Study design

In 2013, we conducted a population-based mortality follow-back survey based on a large and representative sample of deaths ($N = 6871$) in Flanders, Belgium. This study design has been repeatedly applied and validated in earlier studies evaluating end-of-life care and decisionmaking.¹⁶⁻¹⁸ We obtained a stratified random sample of all death certificates from 1 January 2013 to 30 June 2013 of people aged 1 year or older from the Flemish Agency for Care and Health. The survey was conducted from 1 March 2013 to 31 December 2013. Every physician certifying a death certificate in the sample was requested to complete a four-page questionnaire about the end-of-life care and decision-making consulting the patient's medical file. A lawyer served as an intermediary between responding physicians, researchers, and the Flemish Agency for Care and Health, ensuring that completed questionnaires could never be linked to a patient or physician. A one-page questionnaire was mailed to all non-responding physicians, inquiring about the reasons for not participating. The Ethical Review Board of the University Hospital of the Vrije Universiteit Brussel, the Belgian National Disciplinary Board of Physicians, and the Belgian Privacy Commission approved

the mailing and anonymity procedure. Further details on this study and the data collection procedure can be found in previous articles covering this dataset.^{2,16,19,20}

Physicians are required to report euthanasia cases to the Federal Control and Evaluation Committee for Euthanasia which issues biennially a report of all reported cases providing basic statistics.²¹ However, information on involvement of palliative care in end-of-life care is lacking, and there is no requirement to report euthanasia requests that are not carried out.

2.2. Questionnaire

The questionnaire first asked whether the death of the patient had been sudden and unexpected. If answered negatively, physicians were asked about the medical decisions made at the end of the patient's life with a possible or certain life-shortening effect. We identified cases as euthanasia if the physician gave an affirmative answer to the following questions: (1) was the death the consequence of the use of drugs prescribed, supplied or administered by you or another physician with the explicit intention of hastening the end of life or of enabling the patient to end his or her own life? (2) Was the decision made at the explicit request of the patient?

Furthermore, in the questionnaire, physicians were asked whether one or more of the four types of palliative care services in Belgium had been involved in the end-of-life care of the deceased person: palliative care support at home (multidisciplinary teams skilled in palliative care who support the informal caregivers), hospital-based palliative care teams (mobile multidisciplinary teams that guide palliative care in the different wards of the hospital), inpatient palliative care units (separate wards in the hospital devoted to palliative care), and a reference person (usually a nurse) trained in and responsible for palliative care in a nursing home. Where no palliative care services had been involved, the physician was asked about the reasons no such services were used. They were also asked whether one or more caregivers specialized in palliative care were consulted about euthanasia, whether death occurred in a palliative care unit, and whether the attending physician was part of a palliative care team. Demographic and clinical data were obtained from the death certificate and linked anonymously after data collection.

2.3. Data analysis

Data were weighted to correct for the disproportionate stratification of deaths and adjusted to be representative of all deaths in the period covered by the survey in terms of age, sex, marital status, province of death, cause of death, and place of death.

Only people who had expressed a euthanasia request and those who died non-suddenly without having expressed a euthanasia request were selected. We carried out Fisher exact tests and multivariable logistic regression analyses, adjusted for sex, age, cause of death, and place of death, to analyze differences in involvement of palliative care services in end-of-life care between those dying non-suddenly without a euthanasia request and those who expressed a euthanasia request. Fisher exact tests were used to test for differences between those dying non-suddenly without a euthanasia request and those who expressed a euthanasia request in the reasons given by physicians for not referring a patient to palliative care services. Multivariable logistic regression analyses, adjusted for sex, age, cause of death, and place of death, were computed to assess the association between the involvement of palliative care services as the independent variable and the result of the euthanasia request (granted vs not granted) as dependent variable. Further multivariable logistic regression analyses were computed to examine the association between sex, age, cause of death, and place of death as the independent variables and involvement of palliative care professionals (involved vs not involved) as dependent variable. All analyses were performed with the complex samples function in IBM SPSS Statistics (version 24).

3. Results

Questionnaires were returned for 3751 deaths. Response was impossible for 683 because of issues related to patient identification or access to the deceased's medical file. Response rate was 60.6%. Of the 3751 deaths, 2042 (weighted percentage 55.7%) were non-sudden without a euthanasia request having been expressed, 415 (weighted percentage 6.0%) had an expressed euthanasia request, and 349 deaths (weighted percentage 4.6%) were the result of euthanasia.

Of all the people who used palliative care services, 14.1% had expressed a request for euthanasia (data not shown). Palliative care services were more likely to have been involved in the end-of-life care of those who requested euthanasia than of

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those who died non-suddenly without expressing a request for euthanasia (70.9% vs 45.2%, odds ratio (OR) = 2.1 (95% confidence interval (CI), 1.5–2.9)), controlled for sex, age, cause of death, and place of death (Table 7.1). Palliative care services were more likely to have been involved particularly in the deaths of those who had requested euthanasia and were 65 to 79-years old (OR = 3.5 (95% CI, 1.9–6.6) or were dying in hospital (OR = 4.4 (95% CI, 2.3–8.5)).

Table 7.1 Involvement of palliative care services in the end-of-life care of non-sudden deaths without euthanasia request (n=2,042) and deaths with euthanasia request (n=415)

	Non-sudden deaths without euthanasia request		Deaths with euthanasia request		p-value ^a	OR (95% CI) ^b
	Total n (column %)	Palliative care services involved, %	Total n (column %)	Palliative care services involved, %		
Overall		45.2		70.9	<.001	2.1 (1.5-2.9)
Sex						
Male	1015 (48.1)	45.3	210 (50.7)	71.3	<.001	2.2 (1.4-3.4)
Female	1024 (51.9)	45.0	205 (49.3)	70.5	<.001	2.1 (1.3-3.3)
Age						
18-64	284 (12.3)	55.1	95 (21.4)	77.4	.005	1.7 (0.8-3.3)
65-79	588 (26.6)	47.5	147 (34.7)	76.7	<.001	3.5 (1.9-6.6)
80 or older	1167 (61.1)	42.1	173 (43.9)	63.2	<.001	1.9 (1.2-2.9)
Cause of death						
Cancer	858 (28.9)	70.3	255 (56.7)	82.3	.004	1.9 (1.3-2.8)
Non-cancer	1180 (71.1)	35.0	160 (43.3)	54.8	<.001	2.4 (1.5-3.9)
Place of death						
Hospital	854 (50.7)	40.1	106 (39.6)	81.2	<.001	4.4 (2.3-8.5)
Home	550 (19.1)	52.9	234 (42.4)	68.0	.010	1.5 (0.9-2.3)
Nursing home	620 (29.6)	49.1	73 (17.6)	54.7	.506	1.3 (0.7-2.4)
Other	14 (0.6)	34.7	2 (0.4)	79.9	.400	^c

Involvement of palliative care services includes involvement of palliative care support at home, hospital-based palliative care service, palliative care unit, or palliative care reference person in a nursing home.

^aFisher exact test testing for differences in involvement of palliative care services in end-of-life care between non-sudden deaths without euthanasia request and deaths with euthanasia request.

^bComplex samples multivariate logistic regression analyses with involvement of palliative care in end-of-life care as dependent variable (palliative care involved vs palliative care not involved) and presence of a euthanasia request, patient's sex, age, cause of death and place of death as independent variables.

^cOdds ratio could not be calculated.

For people who were not referred to a palliative care service, the most frequently indicated reason for non-referral was that existing care already sufficiently addressed the palliative and supportive care needs, both in those dying non-suddenly without having expressed a euthanasia request (48.3%) and those who had made a euthanasia request (56.5%) (Table 7.2). In 26.1% of people with a euthanasia request, the reason for non-referral was that they did not want to be referred to a palliative care service, compared with 2.8% of those dying non-

Table 7.2 Reasons given by physicians for not referring to palliative care services.

	Non-sudden deaths without euthanasia request not referred to palliative care (n=988) ^b , %	Deaths with euthanasia request not referred to palliative care (n=126) ^b , %	p-value ^a
Reasons given by physicians for not referring to palliative care services			
The care already sufficiently addressed the patient's palliative and supportive care needs	48.3	56.5	.226
Palliative care was not deemed meaningful	34.7	21.7	.048
There was not enough time to initiate palliative care	24.5	14.7	.118
The patient's family did not want it	3.2	5.8	.439
The patient did not want it	2.8	26.1	<.001
Palliative care was not available	1.0	1.0	.450
In order not to deprive the patient and/or family of hope	0.5	0.0	.999

Unweighted numbers and weighted row percentages. More than one reason could be indicated; therefore, percentages may not add up to 100%. Missing values for reasons for not referring to palliative care services: n=78 (7.0%).

^aFisher exact test testing for differences in reasons given by physicians for not referring to palliative care services between non-sudden deaths without euthanasia request and deaths with euthanasia request.

^bOf all non-sudden deaths without euthanasia request (n=2,042) 988 were not referred to palliative care. Of all deaths with euthanasia request (n=415) 126 were not referred to palliative care.

Table 7.3 Euthanasia granting rates according to involvement of palliative care services

	Deaths with euthanasia request, n	Deaths with euthanasia request granted, n	Granting rates of euthanasia requests		
			Palliative care involved, %	Palliative care not involved, %	Odds ratio (95% confidence interval) ^a
Overall	415	349	80.7	78.0	1.2 (0.6-2.5)
Sex					
Male	210	174	77.2	85.2	0.7 (0.2-2.1)
Female	205	175	84.3	70.6	2.5 (0.9-6.9)
Age					
18-64	95	73	72.1	74.1	1.3 (0.3-6.1)
65-79	147	131	82.9	97.2	0.1 (0.01-1.1)
80 or older	173	145	83.4	69.4	3.3 (1.1-9.6)
Cause of death					
Cancer	255	211	79.8	70.3	1.6 (0.7-3.8)
Non-cancer	160	138	82.5	82.3	0.9 (0.3-3.2)
Place of death					
Hospital	106	91	87.5	77.7	2.6 (0.6-11.9)
Home	234	197	75.8	86.2	0.8 (0.3-2.2)
Nursing home	73	60	75.2	64.2	1.7 (0.4-7.6)
Other	2	1	0.0	100.0	^b

Unweighted numbers and weighted row percentages.

^aComplex samples multivariate logistic regression analyses with result of the euthanasia request as dependent variable (granted vs not granted) and involvement of palliative care services, patient's sex, age, cause of death and place of death as independent variables.

^bOdds ratio could not be calculated.

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suddenly without having expressed a euthanasia request ($p < 0.001$). Palliative care not being deemed meaningful was more often indicated as a reason for non-referral for people dying non-suddenly without having expressed a euthanasia request (34.7%) than in those who expressed a euthanasia request (21.7%) ($p = 0.048$).

Overall, no significant differences were found between the likelihood of a euthanasia request being granted in cases where palliative care was involved in end-of-life care and those where it was not (Table 7.3). In people aged 80 years or older, the granting rate was significantly higher when palliative care was involved in end-of-life care: 83.4% of euthanasia requests were granted, compared with 69.4% when palliative care was not involved (OR = 3.3 (95% CI, 1.1–9.6)).

Table 7.4 The role of palliative professionals in the decision-making process and performance of euthanasia^a

	Deaths by euthanasia, n	Palliative care professionals involved in decision-making and/or performance of euthanasia [†] , %	Palliative care professional was consulted about the request, %	Palliative care professional involved in performance of euthanasia	
				Attending physician was part of a palliative care team, %	Euthanasia was performed in a palliative care unit, %
Overall	349	59.8	52.4	21.1	7.4
Sex					
Male	174	58.9	54.9	20.3	5.7
Female	175	60.7	49.9	21.9	9.1
Age					
18-64	73	66.2	54.3	23.6	9.6
65-79	131	60.1	51.0	24.8	11.9
80 or older	145	56.6	52.8	16.7	2.5
Cause of death					
Cancer	211	68.0	57.3	24.3	10.7
Non-cancer	138	48.7	46.0	16.8	3.0
Place of death					
Hospital	91	76.0	65.5	38.0	16.7
Home	197	47.0	42.0	6.8	0.0
Nursing home	60	49.5	44.5	13.5	0.0
Other ^c	1	100.0	100.0	0.0	0.0

Unweighted numbers and weighted row percentages. More than one option could be indicated.

^aFigures in bold denote significant differences ($p < .05$) after complex samples multivariate logistic regression analyses with involvement of palliative care professionals as dependent variable (involved vs not involved) and patient sex, age, cause of death and place of death as independent variables.

^bA palliative care professional was consulted about the euthanasia request, and/or the attending physician was part of a palliative care team and/or euthanasia was performed in a palliative care unit.

^cNot included in the multivariate analysis.

Palliative care professionals were involved in the decision-making process and performance of euthanasia in 59.8% of all deaths by euthanasia (Table 7.4). In 52.4% of performed euthanasia cases, a palliative care professional was consulted about the euthanasia request; in 21.1% of cases, the attending physician was part of a palliative care team; and in 7.4% of cases, euthanasia was performed in a palliative care unit. Palliative care professionals were significantly more often consulted about the euthanasia request and the attending physician was more often part of a palliative care team when the patient died in hospital. When palliative care professionals were involved in the decision-making and performance, the patient's mental suffering was more often indicated as one of the most important reasons for granting the request (50.9% vs 22.4%, $p = 0.002$) (data not shown).

4. Discussion

This population-based study found an involvement of palliative care services in a large proportion of instances of people who died by euthanasia. Palliative care services were involved in the end-of-life care of 70.9% of those who requested euthanasia compared with 42.5% of those who died non-suddenly without having expressed a euthanasia request. The likelihood of a request being granted was not lower in cases where palliative care was involved. Palliative care professionals were involved in the decision-making process and/or performance of euthanasia in 59.8% of all deaths by euthanasia.

While previous studies investigated referral to palliative care and reasons for non-referral¹⁹ and expression and granting of euthanasia requests,² this is the first study focusing on the relationship between the two. Strengths of this study include the use of a mortality follow-back survey conducted among the attending physicians of a representative sample of deaths with a high response rate (61%). This study design is the most feasible and reliable way to study the care delivered shortly before death within a population and, hence, to collect population-based and generalizable information on end-of-life care. However, some study limitations should be considered. First, due to the retrospective nature of the data collection, recall bias cannot be excluded. Second, the restriction of our study to only the perspective of the attending physician may have influenced our findings. As the attending physician may not always be aware of whether palliative care services were involved or whether a patient ever made a euthanasia request to other health professionals, the rate of palliative care service use and euthanasia

requests may have been underestimated. Third, the sensitivity of the survey topic may have introduced the possibility of untruthful or socially desirable reporting, but this is likely to be negligible given the explicit guarantee of anonymity.

Considering the prevailing idea that palliative care and euthanasia are incompatible, it is striking that our study found that requests for euthanasia were associated with higher rates of palliative care involvement, irrespective of the patient's sex, age, diagnosis, and place of death. This corroborates previous research in the United Kingdom and the Netherlands.^{22,23} Furthermore, reports from Oregon and Washington show that a substantial proportion of people who died by physician-assisted suicide were enrolled in hospice.^{24,25} A possible explanation is that physicians want to ensure that all available palliative care options have been considered before granting a request. Furthermore, respecting the patient's wishes, patient autonomy, self-determination, and an emphasis on open communication are key principles of palliative care.¹⁰ This might encourage people to express their thoughts and wishes, including wishes for a hastened death, while in the care of professionals skilled in palliative care.^{22,26} Whatever the underlying reason, our study suggests that in a context of legalized euthanasia, palliative care specialists will often be faced with euthanasia requests.

Moreover, our study found that, at least in Flanders, the involvement of palliative care does not reduce the likelihood that a euthanasia request is granted, and people retain their right to end their lives despite being enrolled in palliative care. This finding is at odds with the widely held belief that palliative care will alter most requests for euthanasia.¹⁰ The finding is also congruent with the official viewpoint on euthanasia and palliative care of the Federation of Palliative Care Flanders¹¹; Flemish palliative care practice indeed seems to accept the possibility of euthanasia in a palliative care context. Other scholars have previously argued that in Belgian end-of-life care, euthanasia and palliative care practices complement rather than oppose each other.^{27,28}

This is further illustrated by the finding that palliative care is often involved in euthanasia procedures, both in consultations about euthanasia requests and in the performance of euthanasia. According to many, this is reasonable and even desirable in a context of legal euthanasia since palliative care professionals are the relevant experts in end-of-life care. Initially, a substantial part of the palliative care community in Belgium was hesitant to become involved in euthanasia practice.¹¹ However, from a sense of duty and the wish not to abandon patients requesting euthanasia, palliative care professionals became increasingly involved in euthanasia practice by supporting the attending physician in the decision-

making process and even in the performance of euthanasia.^{11,28,29} In this way, palliative care professionals put into practice their desire to avoid euthanasia being performed outside the familiar care environment and chose to ensure continuity of care.

There seems to be no lack of access to palliative care for people who request euthanasia (who are willing to see a palliative care specialist), which does not corroborate concerns that people request euthanasia for a lack of access to adequate end-of-life care. Notwithstanding adequate access to palliative care services, many patients—and perhaps their physicians as well—possibly recognize that not all (mental) suffering can be adequately addressed by palliative care.

In about one in four people who requested euthanasia and were not referred to palliative care services, the reason for non-referral was that the patient refused it. A previous study conducted in the Netherlands also found that if palliative care was not involved in a case of euthanasia, this was mainly because the patient had refused it.³⁰ Questions can be raised about whether the legal requirement that the patient's suffering cannot be alleviated can be fulfilled when not all palliative care options have been exhausted. A palliative filter, that is, a compulsory consultation with a palliative care expert when a person requests euthanasia, could address this concern. However, the option of a palliative care filter was not included in the Belgian euthanasia law because it is a patient's right to refuse treatment, including palliative care treatment, and because of fears that some physicians may use the palliative care filter to delay or defer the decision.

5. Conclusion

In Flanders, in the context of legalized euthanasia, euthanasia and palliative care do not seem to be contradictory practices. A substantial proportion of people with a euthanasia request are seen by palliative care services, and for a majority of these, the request is then granted, often with the involvement of palliative care services in the decision-making or the actual performance of euthanasia.

The involvement of palliative care in, and its positive stance toward, euthanasia may be particular to the Belgian situation. However, our study does suggest that health professionals working in palliative care are likely to be confronted frequently with euthanasia requests, regardless of their personal attitudes toward

assisting people in dying. With an increasing number of people worldwide having the legal option of medical aid in dying, the question of how palliative care physicians and nurses respond to those requesting euthanasia becomes highly relevant. The experiences from countries with a legal framework for assisted dying are informative to palliative care communities in jurisdictions considering, or in the process of, legalization of euthanasia. These experiences can help to reflect on the reconciliation of traditional palliative care values with the acceptance of a patient's right to access euthanasia.

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Chapter 8

Euthanasia for people with psychiatric disorders or dementia in Belgium: analysis of officially reported cases

Sigrid Dierickx, Luc Deliens, Joachim Cohen, Kenneth Chambaere

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Abstract

Background – Euthanasia for people who are not terminally ill, such as those suffering from psychiatric disorders or dementia, is legal in Belgium under strict conditions but remains a controversial practice. As yet, the prevalence of euthanasia for people with psychiatric disorders or dementia has not been studied and little is known about the characteristics of the practice. This study aims to report on the trends in prevalence and number of euthanasia cases with a psychiatric disorder or dementia diagnosis in Belgium and demographic, clinical and decision-making characteristics of these cases.

Methods – We analysed the anonymous databases of euthanasia cases reported to the Federal Control and Evaluation Committee Euthanasia from the implementation of the euthanasia law in Belgium in 2002 until the end of 2013. The databases we received provided the information on all euthanasia cases as registered by the Committee from the official registration forms. Only those with one or more psychiatric disorders or dementia and no physical disease were included in the analysis.

Results – We identified 179 reported euthanasia cases with a psychiatric disorder or dementia as the sole diagnosis. These consisted of mood disorders (n=83), dementia (n=62), other psychiatric disorders (n=22) and mood disorders accompanied by another psychiatric disorder (n=12). The proportion of euthanasia cases with a psychiatric disorder or dementia diagnosis was 0.5% of all cases reported in the period 2002–2007, increasing from 2008 onwards to 3.0% of all cases reported in 2013. The increase in the absolute number of cases is particularly evident in cases with a mood disorder diagnosis. The majority of cases concerned women (58.1% in dementia to 77.1% in mood disorders). All cases were judged to have met the legal requirements by the Committee.

Conclusions – While euthanasia on the grounds of unbearable suffering caused by a psychiatric disorder or dementia remains a comparatively limited practice in Belgium, its prevalence has risen since 2008. If, as this study suggests, people with psychiatric conditions or dementia are increasingly seeking access to euthanasia, the development of practice guidelines is all the more desirable if physicians are to respond adequately to these highly delicate requests.

1. Background

The practice of assisted dying is increasingly being discussed in a growing number of countries and is regarded more and more as an acceptable last-resort option for those suffering from severe and irreversible diseases.¹ While assisted dying legislation is restricted to those with terminal illness and a limited life expectancy due to somatic disorder in some US states and Canada, assisted dying for people who are not terminally ill, such as those suffering from psychiatric illness or early stage dementia, is legal in the Netherlands, Belgium and Luxembourg.²

The Belgian Act on Euthanasia stipulates substantive and procedural requirements that must be met for euthanasia to be legally performed.³ As for the substantive criteria, the request for euthanasia must be voluntary, well considered, repeated and not the result of any external pressure. Moreover, the person should be legally competent at the moment of expressing the request. Furthermore, the person must be in a medically futile condition of constant and unbearable physical or psychological suffering resulting from a serious disorder with no reasonable treatment alternatives or therapeutic perspective.

Some specific medical and ethical issues arise regarding these substantive requirements when evaluating the euthanasia request of a person suffering from a psychiatric disorder or dementia. To be able to express a voluntary and well-considered euthanasia request, the person must have sufficient insight into the illness and prognosis and have the capacity to make treatment decisions. In people with a psychiatric disorder or dementia diagnosis, this capacity may be impaired; the desire to die can also be a symptom of the disease.⁴⁻¹⁰ Furthermore, the irreversibility of psychiatric disorders is often questioned since the course of these disorders may fluctuate and can be hard to predict, and prognosis is often uncertain.^{9,11,12}

Procedural requirements include the consultation of a second independent physician and of a third physician if the patient is not expected to die in the foreseeable future. Since those who request euthanasia because of unbearable suffering caused by a psychiatric condition or dementia generally have a longer life expectancy, consultation of a third physician - who should be an expert in the disease according to the law, i.e. a psychiatrist – is required. Moreover, a one-month waiting period is required in these cases between the written request and the performance of euthanasia. Afterwards, physicians must report all cases to the Federal Control and Evaluation Committee on Euthanasia for review.

Although several studies have examined Belgian euthanasia practice both before and after legalization in 2002¹³⁻¹⁷, little is known about the prevalence and characteristics of euthanasia for psychiatric disorders and dementia. In the Committee's biennial summary reports on all reported euthanasia cases, one group is identified as 'neuropsychiatric disorders'¹⁸, but the reports do not mention the precise diagnosis and characteristics of these cases. Recently the popular media have been reporting on high-profile cases involving people with psychiatric disorders. Since people with psychiatric illnesses or dementia are often considered to be an extremely vulnerable patient group, evaluation and monitoring of the euthanasia practice for these persons is vital.

This study aims to describe the trends in reported euthanasia cases with a psychiatric disorder or dementia diagnosis and their characteristics. Only those with one or more psychiatric disorders or dementia and no physical disease are included in the analysis. We will address the following research questions: how has the number of reported euthanasia cases of people with psychiatric disorders or dementia changed between 2002 and 2013, what are the demographic and clinical characteristics of people with psychiatric disorders or dementia who have received euthanasia and what are the characteristics of the decision-making process in reported euthanasia cases of people with a psychiatric disorder or dementia diagnosis.

2. Methods

2.1. Data

The data presented in this article are based on the databases obtained from the Federal Control and Evaluation Committee on Euthanasia that cover all officially reported cases from implementation of the law on September 23, 2002 until December 31, 2013. Euthanasia cases reported from 2014 onwards were not included in the analysis as the Committee had not yet made the data for these years available to the researchers. These databases consist of information collected from the official, standardized euthanasia registration forms sent in by the reporting physicians (see Additional file 1 for the registration form in English, authors' translation). The data are collected by the Committee for evaluation and control purposes; the law allows that they can be made available anonymously

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for academic research purposes in response to a substantiated request to the Committee.³

The databases we received provided the information on all euthanasia cases as registered by the Committee from the official registration forms. The registration form contains both open-ended and closed questions with pre-structured response categories. In the databases we received, open-ended questions such as the patient's precise diagnosis were pre-coded into categories by the Committee. We were able to identify those cases with a psychiatric disorder or dementia because for the category 'neuropsychiatric disorders' the exact disorder was specified in text.

If necessary, data were recoded to obtain consistency over the years in variable coding. Cases with a combination of psychiatric and physical disorders were recoded so that they would not be included in the analysis. Inconsistencies in the data were checked and cleared with the Committee.

2.2. Data analysis

In order to focus strictly on cases of psychiatric disorders and dementia, only those with one or more psychiatric disorders or dementia and no physical disease were included in the analysis, i.e. cases with a psychiatric disorder, such as depression, reported along with a life-threatening somatic illness such as cancer were not included. These cases were divided into four categories: 1) mood disorders, i.e. depressive disorder or bipolar disorder without somatic or other psychiatric disorders, 2) mood disorders accompanied by another psychiatric disorder, 3) other psychiatric disorders, and 4) dementia, including Alzheimer's disease. Dementia, a progressive neurodegenerative condition, was included in the analysis because it is, according to ICD-10, classified under mental disorders (specifically in codes F00 to F03). In the summary reports issued by the Committee, dementia is included in the category of neuropsychiatric diseases along with psychiatric disorders. Issues such as the patient's competence and the patient not being expected to die in the foreseeable future are also pertinent when evaluating these requests for euthanasia.

We used descriptive statistics to report on the annually reported number of cases with a psychiatric disorder or dementia diagnosis and the demographic, clinical and decision-making characteristics for all identified categories. Only descriptive statistics are reported, considering the low number of cases.

3. Results

Between 2002 and 2013, a total of 179 cases with a psychiatric disorder or dementia diagnosis only were identified. The proportion of euthanasia cases with these disorders was 0.5% of all cases reported in the period 2002–2007, increasing from 2008 onwards to 3.0% of all cases reported in 2013 (Table 1). The increase in absolute numbers of cases with a psychiatric disorder or dementia is evident from 2008 onwards (Fig. 8.1), particularly in cases with a mood disorder diagnosis (Fig. 8.2).

Table 8.1 Reported cases of euthanasia with a diagnosis of psychiatric disorder or dementia, 2002–2013

	2002-2007	2008	2009	2010	2011	2012	2013
	No. (%)	No. (%)	No. (%)	No. (%)	No. (%)	No. (%)	No. (%)
No. (% of all reported cases)	10 (0.5)	9 (1.3)	16 (1.9)	19 (2.0)	29 (2.6)	42 (2.9)	54 (3.0)
Mood disorder	4 (40.0)	4 (44.4)	3 (18.8)	7 (36.8)	13 (44.8)	22 (52.4)	30 (55.6)
Mood disorder accompanied by another psychiatric disorder ^a	1 (10.0)	0 (0.0)	0 (0.0)	1 (5.3)	1 (3.4)	4 (9.5)	5 (9.3)
Other psychiatric disorder ^b	0 (0.0)	0 (0.0)	6 (37.5)	3 (15.8)	2 (6.9)	6 (14.3)	5 (9.1)
Dementia	5 (50.0)	5 (55.6)	7 (43.8)	8 (42.1)	13 (44.8)	10 (23.8)	14 (25.9)

Data presented are column percentages.

^aMood disorder accompanied by unspecified personality disorder (5), borderline personality disorder (4), autism (1), anorexia nervosa (1), psychotic personality (1)

^bOther psychiatric disorders were autism (6), borderline (3), posttraumatic stress disorder (2), anorexia nervosa (3), dissociative disorder (1), immature personality disorder (1), psychosis (1), anxiety disorder (1), compulsive disorder (1), paranoid schizophrenia (1), unspecified personality disorder (1), unspecified psychiatric disorder (1)

The 179 cases identified consisted mainly of mood disorders (46.4%) and dementia (34.6%), followed by other psychiatric disorders (12.3%) and mood disorders accompanied by another psychiatric disorder (6.7%) (Table 2).

The majority of euthanasia cases concerned women, with percentages ranging from 58.1% in dementia to 77.1% in mood disorders. Of all the reported euthanasia cases with a mood disorder diagnosis, 38.6% concerned people aged 80 or older. The majority of reported cases concerned people less than 60 years old for mood disorders accompanied by another psychiatric disorder (83.3%) and for other psychiatric disorders (86.4%). Euthanasia most often occurred at home for those diagnosed with other psychiatric disorders (59.1%), mood disorders accompanied by another psychiatric disorder (58.3%), mood disorders (51.8%) and dementia (46.8%). Patients were expected to die in the foreseeable future in 27.4% of those with dementia, 18.2% with another psychiatric disorder, and 8.4% diagnosed with a mood disorder. Physicians most often reported unbearable

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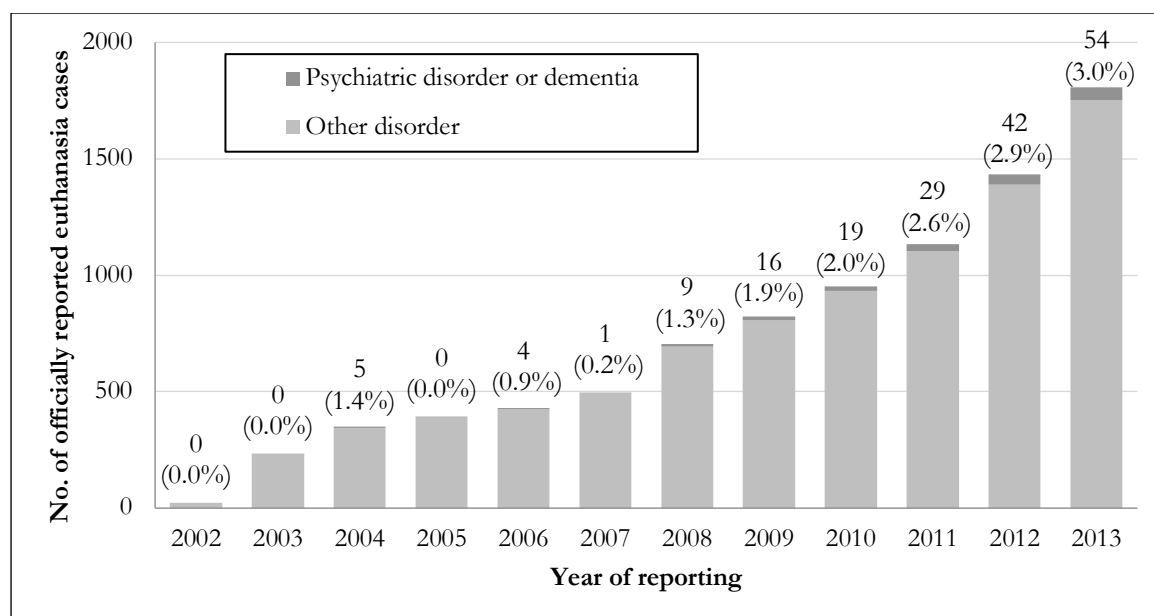


Figure 8.1 Reported cases of euthanasia in Belgium, 2002–2013. Numbers above the bars indicate the number of reported euthanasia cases with psychiatric disorder or dementia diagnosis and the percentage of all reported cases these numbers represent for each year.

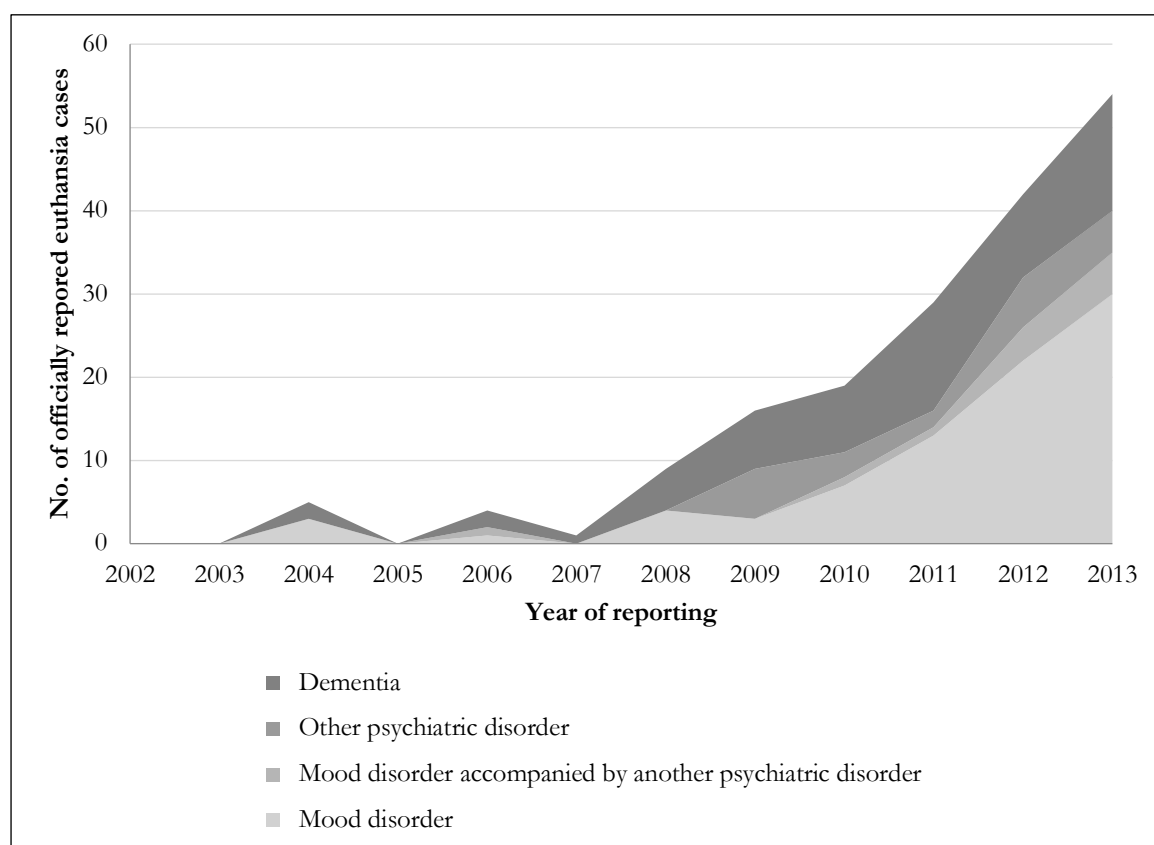


Figure 8.2: Reported euthanasia cases with a diagnosis of psychiatric disorder or dementia, 2002–2013

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Table 8.2 Demographic, clinical and decision-making characteristics of officially reported cases of euthanasia with a diagnosis of psychiatric disorder or dementia, 2002-2013 (n=179)

	Mood disorder, No. (%)	Mood disorder accompanied by another psychiatric disorder, No. (%)	Other psychiatric disorder, No. (%)	Dementia, No. (%)
No. (row %)	83 (46.4)	12 (6.7)	22 (12.3)	62 (34.6)
Demographic characteristics				
Sex				
Male	19 (22.9)	3 (25.0)	7 (31.8)	26 (41.9)
Female	64 (77.1)	9 (75.0)	15 (68.2)	36 (58.1)
Age				
18-59	29 (34.9)	10 (83.3)	19 (86.4)	4 (6.5)
60-79	22 (26.5)	2 (16.7)	2 (9.1)	33 (53.2)
80 or older	32 (38.6)	0 (0.0)	1 (4.5)	25 (40.3)
Clinical characteristics				
Place of death				
Hospital	14 (16.9)	4 (33.3)	6 (27.3)	22 (35.5)
Home	43 (51.8)	7 (58.3)	13 (59.1)	29 (46.8)
Nursing home	23 (27.7)	0 (0.0)	1 (4.5)	10 (16.1)
Other	3 (3.6)	1 (8.3)	2 (9.1)	1 (1.6)
Patient was expected to die in the foreseeable future	7 (8.4)	0 (0.0)	4 (18.2)	17 (27.4)
Reported suffering ^a				
Physical and psychological suffering	23 (27.7)	2 (16.7)	5 (22.7)	24 (38.7)
Only physical suffering	0 (0.0)	0 (0.0)	0 (0.0)	3 (4.8)
Only psychological suffering	60 (72.3)	10 (83.3)	17 (77.3)	35 (56.5)
Decision-making characteristics				
Type of request for euthanasia				
Current request	83 (100)	12 (100)	22 (100)	54 (87.1)
Advance euthanasia directive ^b	0 (0.0)	0 (0.0)	0 (0.0)	8 (12.9)
Specialty of second physician ^c				
Specialist palliative care physician	5 (6.0)	0 (0.0)	3 (13.6)	1 (1.6)
General practitioner	57 (68.7)	6 (50.0)	13 (59.1)	40 (64.5)
Specialist in the illness from which the patient suffers	21 (25.3)	6 (50.0)	6 (27.3)	21 (33.9)
Specialty of third physician if required (N=151) ^d				
Psychiatrist	66 (86.8)	12 (100)	18 (100)	34 (75.6)
Specialist in the illness from which the patient suffers	10 (13.2)	0 (0.0)	0 (0.0)	11 (24.4)
Consultations about the request beyond legal requirements				
One or more consultations	39 (47.0)	8 (66.7)	14 (63.6)	19 (30.6)
Of which with palliative care team(s)	18 (21.7)	3 (25.0)	5 (22.7)	6 (9.7)
Of which with additional physician(s)	26 (31.3)	8 (66.7)	11 (50.0)	16 (25.8)

Data presented are absolute numbers and column percentages.

^aNature of the constant and unbearable suffering that led to euthanasia.

^bEuthanasia based on an advance euthanasia directive is only possible if the patient is in an irreversible coma.

^cThe attending physician must consult a second independent physician about the serious and incurable nature of the disorder.

^dBelgian law distinguishes between those who are expected to die in the foreseeable future and those who are not expected to die in the foreseeable future. A third physician must be consulted if the patient is not expected to die in the foreseeable future. This physician should either be a psychiatrist or a specialist in the illness from which the patient suffers.

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psychological suffering only for euthanasia cases with mood disorders accompanied by another psychiatric disorder (83.3%), other psychiatric disorders (77.3%) and mood disorders (72.3%). The second physician consulted about the request was most often a general practitioner in cases of mood disorder (68.7%), dementia (64.5%), and other psychiatric disorder (59.1%). In cases where the patient was not expected to die in the foreseeable future, the third physician who was consulted about the request was a psychiatrist in all cases with other psychiatric disorders or mood disorders accompanied by another psychiatric disorder, in 86.8% of mood disorders and in 75.6% of dementia cases. Consultation of palliative care teams and/or additional physicians about the euthanasia request, beyond the legal requirements, ranged from 30.6% in cases with a diagnosis of dementia to 66.7% in those with a mood disorder accompanied by another psychiatric disorder.

All notified cases were judged to comply with the due care criteria specified in the Belgian Act on Euthanasia by the Committee.

4. Discussion

Using data on all euthanasia cases officially reported in Belgium from the introduction of euthanasia legislation in 2002 until 2013, this study shows that the number and proportion of euthanasia cases with psychiatric disorders or dementia has gradually increased since 2008. Cases where any physical condition was reported by the attending physician in the euthanasia registration form were excluded from the analysis. The increase is particularly evident in cases with a diagnosis of mood disorder. However, in comparison with the total number of reported cases, euthanasia for these specific groups remains a limited practice.

Because of its controversial nature, the notable increase in euthanasia cases in people with a diagnosis of mood disorder or dementia warrants some exploration of the possible underlying reasons and significance. The trend seems to suggest that the legal possibilities of the euthanasia law are being explored more widely and have become more broadly accepted. Previous research had already shown an increase in euthanasia in groups where the practice was initially much rarer, such as those suffering from conditions other than cancer and those who are not terminally ill.^{17,19} This may reflect a typical process of change where certain groups (both patients and their physicians) slowly explore and adapt to new legal possibilities. The several years of accumulated experience with euthanasia and the

transparency about each case required by the law may have caused an increased uptake of the euthanasia option in groups that were not initially considered to be the target demographic. Additionally, heightened media attention in cases that are often controversial²⁰ may have increased awareness among the general public of the legal possibilities in cases of psychiatric disorder or dementia. Landmark examples in Belgium, for instance, include the case of the euthanasia of Belgian writer Hugo Claus, who suffered from early Alzheimer's disease, in 2008. That case received considerable media coverage. The acceptance by the Federal Control and Evaluation Committee for Euthanasia of certain pioneer cases as being in accordance with the law may have given patients and physicians reassurance that euthanasia in cases with a diagnosis of psychiatric disorder or dementia could be legal if all due care requirements are adhered to properly.

A large majority of Belgian physicians support the option of euthanasia for terminally ill people.²¹ To our knowledge, no data are available regarding Belgian physicians' attitudes towards euthanasia for people suffering from psychiatric disorders or dementia. A Dutch study, however, has shown that a minority of Dutch physicians find it conceivable that they would grant a euthanasia request in the case of a psychiatric disorder (34%) or early-stage dementia (40%).²² In the UK, the majority of physicians are opposed to changes in legislation on assisted dying, with significantly less support in the case of non-terminally ill people.^{23,24}

The increase in euthanasia cases in people with a diagnosis of psychiatric disorder or dementia has given rise to some concerns, one of which relates to the specific competencies of physicians. Dealing with euthanasia requests is a challenging task for physicians, especially so when a request is based on psychological suffering.^{4,9,25} Assessment of decision-making capacity in people with psychiatric disorders is a complex undertaking. However, studies of mental capacity in psychiatric patients show that mental capacity can be reliably assessed.^{26,27} It is not possible, however, to determine whether these assessments were used as this information was not available in the Committee's databases. Further, consensus about the meaning of medical futility in the context of psychiatry is lacking²⁸ and long-term outcomes of psychiatric illness are complicated to determine^{29,30}. Despite all existing and novel treatments for mood disorders³¹⁻³⁵, euthanasia may still be the only option available for certain people suffering from severe treatment-resistant depression. Given the complex nature of euthanasia requests expressed by people with mental illness, it is essential to develop practice guidelines for evaluating and responding to these requests. In 2004 the Dutch

Psychiatric Association issued a guideline for application of the euthanasia law in psychiatric practice³⁶, but no official guideline is available in Belgium.

A second concern relates to the vulnerability of this patient population. People with chronic mental conditions are considered to be a vulnerable population, particularly in the context of assisted dying. As a wish to die can be a symptom of mood disorder, an area of tension arises between respecting the patient's autonomy on the one hand and suicide prevention and harm reduction on the other.³⁷ Further, a rather large proportion (38.8%) of euthanasia cases in mood disorders in our study were in people aged 80 or older. This finding differs from a recent study of 100 people suffering from a psychiatric disorder who requested euthanasia, which found that most cases involved younger people.³⁸ However, our finding is consistent with a study examining psychiatric euthanasia and assisted suicide cases in the Netherlands.³⁹ Older people have an increased risk of having lost a partner, of experiencing social isolation or of the accumulation of chronic physical conditions associated with old age, which are in turn risk factors for depression and are associated with developing a wish to die.^{40–42} However, research also showed that a majority of older respondents with a wish to die suffered from depressed mood without meeting the diagnostic criteria to qualify for a depressive disorder.^{40,41} This emphasizes the importance of careful assessment of euthanasia requests expressed by this population.

A third concern relates to the procedures used to evaluate euthanasia requests in persons with psychiatric disorders or dementia. Considering the potential effect of mental illness on decision-making capacity, the possibility exists that the desire to die is a symptom of the disorder, and, since the prognosis is difficult to make, questions can be raised regarding the need for supplementary monitoring of cases involving people with psychiatric disorders or dementia. For instance, some have suggested additional monitoring through the appointment of a separate subcommittee to review and control these specific cases or through a priori control of euthanasia requests based on unbearable suffering resulting from a psychiatric disorder. Although this procedure may not be desirable for terminally ill people as it can create unnecessary delay, it may be relevant to consider it for requests expressed by people diagnosed with a psychiatric disorder or dementia.

Although it is a legal requirement to do so, a psychiatrist was not consulted in all cases with a diagnosis of psychiatric disorder. A possible explanation for this is that physicians may have only mentioned the diagnosis that was the main cause of the unbearable suffering; it may be that in these cases the person suffered from

multiple pathologies, in which cases the Committee agreed that the legally required third physician could be a general practitioner.

Surprisingly, the reporting physician indicated in a number of cases with a psychiatric disorder diagnosis that the patient was expected to die in the foreseeable future. The Committee defines this as when death can be expected within the next few days, weeks or months, which implies that additional procedural requirements have to be followed in cases of non-progressive or slowly evolving disorders¹⁸, which includes psychiatric disorders. However, if the patient was expected to die in the foreseeable future, but two physicians were consulted about the euthanasia request and the one-month waiting time was respected, the Committee deems these cases in accordance with the law. A possible explanation for our finding is that these people were severely weakened as a consequence of the psychiatric disorder or dementia they were suffering from, leading to death being expected in the near future. An alternative explanation is that the person also suffered from a terminal condition not registered in the database or in the registration form; the reporting physician may have only mentioned the condition that led to the euthanasia request and not the presence of another advanced chronic illness that was not itself the reason for the request. Another possibility is that 'in the foreseeable future' is interpreted broadly by the reporting physician; it is also possible that the physician may have expected the patient to commit suicide in the near future. These cases, although there are only a few of them, illustrate that the evaluation of euthanasia requests from people with serious mental illness may require a different or more complex procedure.

One strength of this study is the use of data based on routinely collected information from the official, standardized euthanasia registration forms; the Committee contacted the reporting physicians when important information was missing from the registration form. Another is that we studied all reported cases of euthanasia with a psychiatric disorder diagnosis in an entire jurisdiction since the implementation of the Belgian Act on Euthanasia in 2002, making it possible to study year-by-year trends.

The study also has limitations. The data were gathered for review and control purposes and coded by the Committee. Certain information from the registration form that could provide more detailed insights into the characteristics and decision making of the selected euthanasia cases was not recorded in the databases, e.g. the reasons why the patient's suffering could not be alleviated or the patient's treatment history. Furthermore, only cases reported to the

Committee could be analysed and not those which were unreported. Due to the complex and controversial nature of euthanasia in cases involving a psychiatric disorder or dementia, it is possible that not all were reported, especially in the earlier years after legalization.⁴³ Furthermore, as there is a requirement to report a euthanasia request which is carried out but not one which is not, we had no information on the number of actual requests for euthanasia coming from those who suffer from psychiatric disorders or dementia. Therefore, it is not possible to report on the number of requests granted, refused or withdrawn.

5. Conclusions

While euthanasia on the grounds of unbearable suffering caused by a psychiatric disorder or dementia remains a relatively limited practice in Belgium, its prevalence has risen since 2008. If, as this study suggests, people with psychiatric conditions or dementia are increasingly seeking access to euthanasia, the development of practice guidelines is all the more desirable if physicians are to respond adequately to these highly delicate requests.

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Chapter 9

How accurately is euthanasia reported on death certificates in a country with legal euthanasia: a population-based study

Joachim Cohen, **Sigrid Dierickx**, Yolanda WH Penders, Luc Deliens, Kenneth Chambaere

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Abstract

Background – Death certificates are the main source of information on the incidence of the direct and underlying causes of death but may be unsuitable for monitoring the practice of medical assistance in dying, e.g. euthanasia, due to possible underreporting. This study examines the accuracy of certification of euthanasia.

Methods – Mortality follow-back survey using a random sample of death certificates (N=6871). For all cases identified as euthanasia we checked whether euthanasia was reported as a cause of death on the death certificate. We used multivariable logistic regression analysis to evaluate whether reporting varied according to patient and decision-making characteristics.

Results – Through the death certificates, 0.7% of all deaths were identified as euthanasia, compared with 4.6% through the mortality follow-back survey. Only 16.2% of the cases identified from the survey were reported on the death certificate. Euthanasia was more likely to be reported on the death certificate where death was from cancer (14% covered), neurological diseases (22%) and stroke (28%) than from cardiovascular disease (7%). Even when the recommended drugs were used or the physician self-labelled the end-of-life decision as euthanasia, euthanasia was only reported on the death certificate in 24% of cases.

Conclusions – Death certificates substantially underestimate the frequency of euthanasia as a cause of death in Belgium. Mortality follow-back studies are essential complementary instruments to examine and monitor the practice of euthanasia more accurately. Death certificate forms may need to be modified and clear guidelines provided to physicians about recording euthanasia to ensure more accurate certification.

1. Introduction

Death certificates serve as the main source of information about the incidence of direct and underlying causes of death. Since euthanasia and physician-assisted suicide are legal in a number of countries and several states in the USA¹, these are accepted as an immediate cause of death on death certificates in these jurisdictions. In Belgium, for instance, euthanasia (legally defined as the intentional ending of life by a physician at the person's explicit request) has been an accepted cause of death on the death certificate since its legalization in 2002.² Since then euthanasia cases are to be reported on the death certificate as natural deaths by ticking the appropriate check box (see figure S9.1, supplemental appendix)^{2,3} and can be certified as the direct cause of death in the WHO-standardized cause of death reporting scheme. The agency processing the death certificate data then codes all certified euthanasia cases with the ICD-10 code Z41.

With euthanasia being certified in this way, it would theoretically be possible to make yearly incidence estimations based on analysis of death certificates. However, this is only possible if death certificates can be relied on to cover almost all cases of euthanasia. Comparison of the incidence of euthanasia as certified through death certificates with euthanasia as reported through anonymous mortality follow-back surveys using death certificates as a sampling framework allows investigation of how complete the certification of the practice of euthanasia is.^{4,5}

Our study examined what proportion of deaths in Flanders, Belgium is the result of euthanasia as estimated through the death certificate compared with an anonymous mortality follow-back survey, and which patient and practice characteristics are associated with euthanasia being reported on the death certificate. The hypothesis was that death certificate data substantially underestimate the total practice of euthanasia.

2. Methods

Our study compares information obtained through a mortality follow-back survey using a random sample of death certificates with the information recorded on those death certificates. The mortality follow-back study consisted of a representative sample of 6,871 death certificates in Flanders, the semi-

autonomous northern half of Belgium, between 1 January and 1 June 2013, about 21% of all deaths in the period. Stratification was done by cause of death, with an increased sample ratio of deaths known to have a higher likelihood of involving an end-of-life decision such as euthanasia e.g. cancer.⁵ Certifying physicians were sent a questionnaire about the end-of-life care and decision-making that preceded the death. The questionnaire did not ask about euthanasia directly as this could introduce bias due to individual interpretations of the term and to responses affected by social desirability.⁵⁻⁷ Instead, a case of euthanasia was identified based on an affirmative answer from the physician to the questions 1) was the death the consequence of the use of drugs prescribed, supplied or administered by you or another physician with the explicit intention of hastening the end of life or of enabling the patient to end his or her own life?, and 2) was the decision made at the explicit request of the patient? Additional questions asked about the decision-making process and the drugs used, and which term was considered to best fit the reported medical practice.

The Ethical Review Board of the University Hospital of the Vrije Universiteit Brussel, the Belgian National Disciplinary Board of Physicians, and the Belgian Privacy Commission approved the mailing and anonymity procedure.

We corrected the questionnaire response samples for disproportionate stratification and nonresponse bias to be representative of all deaths. Multivariable logistic regression analyses, using the complex samples procedure, were performed to evaluate what patient and decision-making characteristics were associated with an increased likelihood that euthanasia, as identified via the mortality follow-back study, was reported on the death certificate, controlling for the confounding effects of other variables. Analyses were done in IBM SPSS (version 24). Cases of physician-assisted suicide (if the patient self-administered the drugs) are counted as euthanasia in this study. This is in line with the Belgian euthanasia review committee which considers physician-assisted suicide as a form of euthanasia as long as all due care requirements are met.

3. Results

Response rate was 60.6%. Through the death certificates, 0.7% (weighted %, unweighted n=179) of all deaths were identified as euthanasia, compared with 4.6% (weighted %, unweighted n=349) through the questionnaire (Table 9.1). In 16.2% of all euthanasia cases identified in the survey the certifying physician

Reporting of euthanasia on death certificates

Table 9.1 Comparison between euthanasia incidence estimated based on the death certificate^a or based on the mortality follow-back survey (n=528)^f

	Total N surveyed	Death certificate	Survey	% covered ^b	OR (95% CI)
Unweighted N	3751	179	349		
Total (%) ^c	100.0	0.7	4.6	16.2	
Sociodemographics^c					
Sex					
Male	1895	0.7	4.6	14.3	Ref.
Female	1852	0.8	4.6	18.2	1.2 (0.9-1.6) ^d
Age					
1-64	583	1.0	5.6	18.5	1.4 (0.9-2.2) ^d
65-79	1024	1.0	6.4	16.4	1.5 (1.0-2.1) ^d
80+	2140	0.5	3.5	15.0	Ref.
Cause of death					
Cardiovascular	882	0.1	2.3	6.6	Ref.
Cancer	937	1.5	10.6	14.4	2.3 (1.5-3.5)^d
Respiratory	395	0.2	1.8	8.5	1.5 (0.6-3.9) ^d
Neurological	201	1.4	6.3	22.4	3.3 (1.5-7.2)^d
Stroke	254	0.5	1.8	28.2	5.1 (1.6-15.8)^d
Other	1057	0.7	2.8	26.5	5.2 (2.7-9.9)^d
Educational attainment					
None or primary	1396	0.4	2.5	15.7	Ref.
Lower secondary	967	0.7	3.8	19.4	1.3 (0.7-2.4) ^d
Higher secondary or higher	629	0.8	6.9	12.2	0.7 (0.4-1.1) ^d
Missing	759	0.9	5.1	18.3	1.2 (0.8-2.1) ^d
Administration of drugs with explicit intention to hasten death, using^c					
Barbiturates and/or muscle relaxants	270	23.4	100	23.4	Ref.
Benzodiazepines with or without opiates	63	2.4	49.0	0.5	0.02 (0.09-0.03)^e
Opiates	60	0.0	45.0	0.0	0.0 (0.0-0.0)^e
Other	8	3.8	63.8	6.0	0.4 (0.1-1.0)^e
Self-labelling of end-of-life decision^c					
Euthanasia	275	24.2	99.5	24.4	Ref.
Ending of life out of compassion	9	1.1	12.3	8.6	0.4 (0.1-1.9) ^e
Palliative or terminal sedation	412	0.0	12.7	0.3	0.01 (0.01-0.01)^e
Intensified alleviation of pain or other symptoms	636	0.0	1.4	0.0	-
Non-treatment decision	460	0.03	0.4	6.5	0.1 (0.01-0.7)^e

Other term or no term chosen	179	0.0	0.0	-	-
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CI=Confidence interval; OR=Odds ratio

^a: Euthanasia as indicated on the death certificate. In Belgium indicated in text as one of the causes of death using the WHO standardized cause of death certification system. Any case of euthanasia is coded in ICD-10 with the code 'Z41'.

^b: percentage covered is calculated on raw data and may not be reproducible from the rounded figures given in the table. Raw data available from authors on request.

^c: Percentages are weighted to be representative of all deaths in Flanders between 01-01-2013 and 30-06-2013. Percentages are weighted to correct for non-response bias and disproportionate stratification. The strata are based on the cause of death as reported on the death certificate and the estimated corresponding likelihood of an end-of-life decision (including euthanasia): all deaths within the sampling period for which euthanasia was mentioned on the death certificate were sampled; 1/3 of cancer deaths and 1/6 of deaths from any other cause. Percentages are row percentages.

^d: Multivariable odds ratio controlling for sex, age, and cause of death. Bold denotes statistically significant at $p < 0.05$.

^e: Multivariable odds ratio controlling for drugs used, self-labelling of end-of-life decision, sex, age and cause of death. Bold denotes statistically significant at $p < 0.05$.

^f: Two cases that were indicated as euthanasia on the death certificate but not in the survey were excluded, as we used the survey as the starting point under the assumption that euthanasia is defined as the intentional ending of life by a physician at the person's explicit request and a negative answer on the survey indicates there was no request from the patient, no action taken to hasten death, or neither.

^g: The administration of drugs with explicit intention to hasten death does not necessarily imply that euthanasia was performed, as the drugs could have been administered without an explicit patient request.

^h: Self-labelling was only asked in case an end-of-life decision was made; 179 cases where no term was provided or the option "other term" was indicated are left out of the table.

indicated euthanasia as cause of death on the death certificate. The percentage of cases identified through the questionnaire that were covered by the death certificate did not differ in terms of age or sex. Euthanasia was less likely to be reported on the death certificate if the patient died of cardiovascular disease (6.6% covered) than of cancer (14.4% covered), neurological disease (22.4% covered), stroke (28.2% covered), or other causes (26.5% covered), also after controlling for sex and age.

Identified euthanasia cases were more often certified when barbiturates and/or muscle relaxants were used with the explicit intention of hastening death (23% covered) than when benzodiazepines (0.5% covered) or opioids (0% covered) were used for that purpose (Table 2). Cases of euthanasia for which the physician indicated in the questionnaire that "euthanasia" was the best fitting term to describe the practice were reported on the death certificate as euthanasia in 24%, which was more than for euthanasia cases labelled by the physician as "ending of life out of compassion" (9%), "palliative or terminal sedation" (0.5%), "intensified alleviation of pain or other symptoms" (0.5%), or "non-treatment decision" (7%). Multivariable logistic regression controlling for sex, age, and cause of death confirmed these differences.

4. Discussion

The substantial underreporting of euthanasia on death certificates found in this study suggests that death certificate data are insufficient to investigate the incidence of the practice, even in jurisdictions where it is legal. Differences in the probability of euthanasia being certified according to the underlying cause of death additionally suggests that cases reported on death certificates are not representative for all euthanasia cases. Non-certification of euthanasia may be due to physicians consciously or unintentionally not recognizing their cases of euthanasia as such^{6,7} because they believe that they have not complied with the legal due care criteria (e.g. not reported euthanasia to the evaluation committee as is required by law), because they have privacy concerns for themselves – as reporting attaches their name to the euthanasia case – and the patient, and because they do not consider it necessary to report it on the death certificate. The lack of clear guidelines is probably also a reason for the low number of euthanasia cases indicated on death certificates. After the euthanasia law was passed in Belgium, the death certificate format remained unchanged and the only instruction given to physicians was that euthanasia should be indicated as a natural death.² Other certifying systems, such as providing a separate checkbox for euthanasia as is done in the Netherlands, may in combination with clearer instructions lead to a more complete recording of the practice. By changing the death certificate in this way, the monitoring of the practice of euthanasia through death certificates could become more reliable. On the other hand, it may be that estimating the number of euthanasia-related deaths will be impossible altogether in some jurisdictions with legal euthanasia. For example, in the context of the parliamentary debate on euthanasia in Victoria, Australia, a taskforce designing the legal framework for euthanasia advised that physicians should not indicate euthanasia on the death certificate to safeguard the life insurance of the person who has died, which may not be paid out in cases of euthanasia as this could be seen as suicide.⁸ One may argue that recording euthanasia on the death certificate is not essential because they primarily serve the purpose of giving insights into epidemiological developments rather than into medical practices. On the other hand, euthanasia is a manner of death and, particularly in jurisdictions where its prevalence is high, can have an impact on mortality patterns. Its explicit inclusion on the death certificate could provide societies with a useful monitoring tool for its practice and impact on mortality patterns.

The mortality follow-back design used here is highly suited to answering questions on the certification of euthanasia and to monitoring the practice of

euthanasia on a population level. By avoiding the term euthanasia but using a description of the practice we are able to identify cases of euthanasia that would not otherwise be known, regardless of the physician's personal interpretation or opinion of euthanasia. However, while using an indirect way of identifying euthanasia avoids social desirability and individual bias affecting responses, it is possible that a limited number of cases identified as euthanasia fall into a grey area and may not, strictly speaking, have been euthanasia. Nevertheless, the results show that even when a physician self-labels the end-of-life decision as euthanasia, and when barbiturates with or without muscle relaxants are used in accordance with recommended practice⁹, still fewer than a quarter of cases are reported on the death certificate as euthanasia. This means that even inclusion of a few grey area cases would not affect our overall conclusions.

While a relatively high response rate was achieved compared to most physician surveys, we cannot exclude non-response bias. Although comparison of the response and non-response cases revealed no significant differences in terms of sex, age and cause of death, and slight differences in terms of place of death and province, it cannot be excluded that, for instance, physicians who were less inclined to disclose their end-of-life practice on the death certificate were also less inclined to do so in a questionnaire. Analysis of the non-response cases revealed lack of time as the most frequent reason for non-participation. The explicit guarantee of anonymity and the use of descriptive terms instead of 'euthanasia' in the questionnaire have probably mitigated that bias.

In conclusion, death certificates substantially underestimate the frequency of euthanasia as a cause of death in Belgium and are therefore an unreliable tool for monitoring its practice. For a more complete certification of euthanasia in jurisdictions where it is legal, consideration may need to be given to modifying the death certificate form and providing clear guidelines to physicians about whether and how they should record euthanasia on the death certificate. Our study illustrates that mortality follow-back studies are an essential complementary instrument for examining and monitoring the practice of euthanasia more accurately.

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PART IV

GENERAL DISCUSSION AND CONCLUSIONS

Chapter 10

General discussion and conclusions

1. Introduction

The aim of this dissertation was to provide population-based evidence on general trends in euthanasia practice in Belgium and on particular current issues being debated regarding euthanasia. This dissertation addressed seven research questions in chapters 3 to 9.

Four research questions dealt with trends in euthanasia practice:

- 1 Which trends have occurred in officially reported euthanasia cases with regard to patient's sociodemographic and clinical profiles, as well as decision-making and performance characteristics? (Chapter 3)
- 2 Which trends have occurred in the expression and granting of euthanasia requests and the reasons that physicians granted or denied these requests? (Chapter 4)
- 3 What are the changes over time in drugs used to perform euthanasia and what are the differences in case characteristics according to the drugs used? (Chapter 5)
- 4 What are the differences and commonalities in euthanasia and assisted suicide practice in Belgium, the Netherlands and Switzerland? (Chapter 6)

Three research questions considered current debates regarding euthanasia practice:

- 5 To what extent are palliative care services involved in the care of people requesting euthanasia, and in the decision-making and performance of euthanasia? (Chapter 7)
- 6 How has the prevalence and number of reported euthanasia cases with a psychiatric disorder or dementia diagnosis changed in Belgium and what are the demographic, clinical and decision-making characteristics of these cases? (Chapter 8)
- 7 How accurately is euthanasia reported on death certificates? (Chapter 9)

In this part of the dissertation, the main findings of the included studies are discussed. First, the methodological strengths and limitations of the included studies are considered, followed by a summary of the main findings. Next, a general discussion will explore the results in depth and will relate the findings to previous research. Finally, a number of implications and recommendations for policy, practice, and future research are outlined.

2. Methodological strengths and limitations

We used two types of studies to answer our research questions. Firstly, we performed a secondary analysis of the official databases of all euthanasia cases reported to the Federal Control and Evaluation Committee for Euthanasia (FCECE). We obtained the databases of all officially reported cases of euthanasia in Belgium since implementation of the euthanasia law on September 22, 2002 until December 31, 2013. Secondly, we conducted a mortality follow-back study using a representative sample of death certificates. In this study a stratified random sample of death certificates of those aged one year or older was drawn in Flanders, Belgium.¹ The physician who certified the death certificate was sent a questionnaire on the end-of-life decision-making in the death concerned. Both studies have their specific strengths and limitations which will be discussed in this paragraph.

A limitation applying to both study methods used in this dissertation is that both studies are based solely on information provided by physicians. As the perspectives of patients, patients' relatives or care providers involved in the patient's end-of-life care other than the physician are lacking, we do not have any

information on their experiences. As a consequence, the studies only provide a partial picture of euthanasia characteristics, decision-making processes and end-of-life care for persons who died by euthanasia. Also, in both studies there is the possibility of social desirability bias because of the sensitive nature of the research topic. In the study of euthanasia cases reported to the FCECE physicians may have presented their cases as fully in compliance with the euthanasia law in order not to risk possible criminal prosecution. In the mortality follow-back study social desirable answers may have occurred for instance in the questions on the intention of the medical end-of-life decision and whether or not euthanasia was reported to the FCECE.

2.1. Analysis of the data collected from the euthanasia cases reported to the Belgian Federal Control and Evaluation Committee for Euthanasia

2.1.1. Strengths of the study

We studied all euthanasia cases reported to the FCECE since implementation of the euthanasia law on September 23, 2002 until December 31, 2013 (N=8,776). As all reported cases were included in the analysis and thus no sample was taken, the data are representative for the total population of reported euthanasia deaths in Belgium during this period. A further strength is that the data were gathered using a standardized registration form which has not been changed since the beginning of the data collection. This makes it possible to make reliable conclusions regarding year-by-year trends in the characteristics of reported euthanasia cases. Also, in cases where the FCECE was faced with matters that were unclear, the reporting physician was contacted for clarifications.² A final strength is that the FCECE collects data for both Dutch-speaking and French-speaking Belgium.

2.1.2. Limitations of the study

Despite its strengths, our study of reported euthanasia cases is also subject to certain limitations. We analysed secondary data routinely collected as part of the mandatory notification procedure for review and control purposes. A thorough empirical study of reported cases of euthanasia was not the primary goal of the FCECE. In addition, the data were coded by the FCECE and therefore, we had

no control over quality and consistency of coding and data input. Also, information from the registration form that could provide more detailed insights into the characteristics and decision-making of the euthanasia cases was not recorded in the databases e.g. the precise nature of the suffering that caused the patient to seek euthanasia, the reasons why the patient's suffering could not be alleviated, the patient's treatment history or the consulted physicians' advice. With regard to the content of the registration form, certain information that could be relevant for our analysis was not asked, e.g. (palliative) treatment options discussed with the patient, (palliative) treatment options used, date of (first) request for euthanasia, involvement of LEIF physicians (either reporting physician or consulted physicians), time between drugs administration and death, or possible complications during the euthanasia procedure or performance. Some of these issues can be mentioned by the physician but are not asked explicitly in the registration form.

A further limitation is that the data provide insight into only those euthanasia cases that were reported to the FCECE. It has been shown that not all euthanasia cases were reported to the FCECE and that unreported cases were generally dealt with less carefully than reported cases.³ Lastly, there is a requirement to report a euthanasia request which is carried out, but not one which is not. Therefore, we had no information on the number of actual requests for euthanasia. This makes it also impossible to report on the number of euthanasia requests granted, refused or withdrawn based on the FCECE's data.

2.2. Mortality follow-back survey using a representative sample of death certificates

2.2.1. Strengths of the study

The mortality follow-back survey using a representative sample of death certificates has been proven to allow reliable estimations of incidences of end-of-life decisions, including euthanasia and assisted suicide, in a population.⁴⁻⁷ An important strength of this study is the use of death certificates. Firstly, use of death certificates makes it possible to draw a large population-based sample, allowing reliable data representative for an entire period. As the sample is composed of a random sample of death certificates, all deaths have a theoretically equal probability to be included in the study. Secondly, there are no restrictions regarding the patient population and care settings as the sample includes all relevant patient groups and care settings. Thirdly, it is easy to identify and contact

the appropriate information unit i.e. the physician, who is best placed to provide the necessary information on end-of-life decision-making. Lastly, using death certificates allows for linking data from the death certificate to data from the questionnaire. This way, information such as the patient's sociodemographic characteristics, cause of death and place of death are available from the death certificates and do not need to be collected through the questionnaire.

We used disproportionate stratified sampling based on the reported cause of death in order to have more cases – and more statistical power and reliability of the data – for rare end-of-life decisions such as euthanasia. Afterwards, the data were weighted to correct for this disproportionate stratification. In 1998 – when no disproportionate sampling was used – the sample included 25 cases of euthanasia and physician-assisted suicide compared to 142 cases in 2007 and 349 cases in 2013.

Some strengths are related to the questionnaire used in this study. Firstly, the questionnaire has been repeatedly validated in Belgium as well as in other countries, where this study design has been used several times.⁴⁻⁶ While some questions have been added in the most recent version, such as the question regarding involvement of palliative care services, the key questions to identify end-of-life decisions, including euthanasia, have remained unchanged. This allows for reliable study of trends over the years and between countries. Secondly, the questionnaire used descriptive questions to identify cases of euthanasia and assisted suicide. Euthanasia and assisted suicide are value-laden terms and are often subject to different interpretations. To identify euthanasia cases, descriptive questions are used without mentioning 'euthanasia' or 'assisted suicide' to avoid socially desirable answers and possible differences in interpretation of what constitutes euthanasia and what does not.

Response rates for mail survey studies among physicians are generally low, with a median response rate of 43% for large sample surveys.^{8,9} To limit nonresponse as much as possible, we followed Don A. Dillman's Total Design Method¹⁰ by using an intensive follow-up mailing procedure of three reminders per death case. Considering the median response rate found in other physician surveys and the sensitivity of the research topic, we achieved an acceptable to fairly high response rate ranging from 48% in 1998 to 61% in 2013. We performed a nonresponse survey which found that physicians most frequently indicated lack of time as reason for non-participation. Comparison of the response and non-response cases revealed no significant differences in terms of sex, age and cause of death, and only slight differences in terms of place of death and province.

Taking into account that the practice of euthanasia can be considered to be a sensitive research topic, a thorough anonymity procedure was used for data collection. As studies have shown that physicians will generally not complete a survey if there are any doubts regarding confidentiality^{11,12}, strict anonymity was guaranteed through a complex mailing procedure involving the researchers, the Agency for Care and Health, a sworn-in lawyer and the participating physicians.

2.2.2. Limitations of the study

This study design also has some limitations. Recall bias and memory bias may have influenced our study results. With regard to recall bias, physicians are asked questions about a death that occurred sometime before filling in the questionnaire. Physicians' recollections of the specific circumstances of decision-making and end-of-life care before the patient's death may have been incomplete. Memory bias influences the content of a recalled memory. Especially with regard to the value-laden practice of euthanasia and assisted suicide, certain memories may be enhanced or impaired due to errors in physicians' own perception of the medical act. To mitigate recall bias and memory bias, physicians routinely received the questionnaire no later than eight weeks after the patient's death. Also, physicians were encouraged to consult the patient's medical file when filling in the questionnaire.

The use of death certificates entails some disadvantages. Firstly, the physician who completes the death certificate is not always the attending physician. To overcome this problem, physicians were asked in the letter accompanying the questionnaire to pass on the questionnaire to the treating physician in case the certifying physician was insufficiently informed on the end-of-life care and decision-making of the patient. Secondly, because death certificates are used as sampling base, the death case is the unit of measurement. This implies that one physician can have certified multiple deaths in the sample. In this study, the maximum number of death cases one physician could be asked to report on was limited to five. Responder fatigue even before the physician reaches this cut-off may have occurred. Nonresponse on the part of these physicians can thus not be excluded. We observed that mainly after three death cases response dropped considerably. Thirdly, some have pointed out inaccuracies in cause of death recording through death certificates.^{13,14} Inaccuracies may include incorrect cause of death certification or misclassification and possible variation between countries (impeding international comparison) or between different health care settings within one country.

Euthanasia and assisted suicide cases are identified if the physician gives an affirmative answer to the following questions:

- 1) Was the death the consequence of the use of drugs prescribed, supplied or administered by you or another physician with the explicit intention of hastening the end of life or of enabling the patient to end his or her own life?
- 2) Was the decision made at the explicit request of the patient?

These questions largely correspond to the legal definition of euthanasia. However, while the legal definition of euthanasia uses ‘termination of life’ (*‘levensbeëindiging’*), the study questionnaire uses the term ‘hastening the end of life’ (*‘het levenseinde bespoedigen’*). It cannot be precluded that this difference, albeit small, might have influenced physicians’ answers. This may have important consequences regarding the interpretation of discrepancies we observed between what constitutes euthanasia as identified through the survey and physicians’ perceptions of their medical acts.

3. Summary of the main findings

The main findings for each research question are summarized below.

3.1. Trends in euthanasia practice

3.1.1. Trends in euthanasia cases reported to the Federal Control and Evaluation Committee for Euthanasia

In Chapter 3, we described trends in patient characteristics and decision-making and performance characteristics of euthanasia using the database of all euthanasia cases (n=8752) reported to the FCECE between January 1, 2003 and December 31, 2013. This study showed that the number of reported euthanasia cases increased year by year, from 235 (0.2% of all deaths) in 2003 to 1807 (1.7% of all deaths) in 2013. The rate of euthanasia increased significantly among those aged 80 years or older, those who died in a nursing home, those with a disease other than cancer and those not expected to die in the near future. Reported cases in 2013 most often concerned those with cancer (69%) and those under 80 years (65%). Palliative care teams were increasingly often consulted about euthanasia requests, beyond the legal requirements to do so. Among cases reported in

Dutch, the proportion in which the person was expected to die in the foreseeable future decreased from 94% in 2003 to 84% in 2013, and palliative care teams were increasingly consulted about the euthanasia request (from 34% in 2003 to 43% in 2013). These trends were not visible for cases reported in French. Considering the increases observed among non-terminally ill and older people, our analysis shows the importance of detailed monitoring of developments in euthanasia practice.

3.1.2. Shifts in the expression and granting of euthanasia requests

In Chapter 4, we reported on the results of a population-based mortality follow-back study in 2013. We compared these with the results of an identical study conducted in 2007. We found that the prevalence of euthanasia increased in all patient groups and in all health care settings. The prevalence of euthanasia requests increased from 3.4% in 2007 to 5.9% in 2013 and the proportion of requests granted increased from 55% to 77%. The most pronounced increases in the frequency of requests were in those who were 80 years or older (2% to 5%), those with a college or university education (5% to 13%), and those with a diagnosis of cardiovascular disease (0.8% to 3%). The largest increases in the rates of granting requests were among women (46% to 76%) and those who were 80 years or older (38% to 75%), had lower education attainment (35% to 69%), and died in nursing homes (23% to 68%). In 2013, physicians reported that the most important reasons for granting a euthanasia request were the patient's request (88%), physical and/or mental suffering (87%) and the lack of prospects for improvement of their condition (78%). The most important reasons for not granting the request were that the patient died before the decision (59%), the request was revoked (18%), and legal criteria were not met (20%). The percentage of cases in which the physician reported denying the request for reasons external to the patient, including restrictive institutional policy, personal objections, or fear of legal consequences, decreased from 23% in 2007 to 2% in 2013. In conclusion, the proportion of dying people who make a euthanasia request has substantially increased across various patient groups and, following 11 years of experience with the practice, physicians are more willing to grant these requests.

3.1.3. Changes over time in drugs used to perform euthanasia

In Chapter 5, we studied drugs used to perform euthanasia, and how this has changed since before the euthanasia law, euthanasia case characteristics

(decision-making and administrative characteristics, physicians' perceptions of their act and reporting) in relation to the types of drugs used to perform euthanasia, and time trends in euthanasia case characteristics in relation to drugs used to perform euthanasia. Use of recommended drugs to perform euthanasia increased from 11.9% of euthanasia cases in 1998 to 55% in 2007 and 67% in 2013 ($p < 0.001$). Opioids only or with other drugs (excl. barbiturate, neuromuscular relaxant or benzodiazepine) were the most often used non-recommended drugs in 2013 (16%). In 2013, cases with recommended drugs compared to non-recommended drugs more often involved requests expressed both orally and in writing (87% vs 14%, $p < 0.001$), consultation with colleague physicians (94% vs 69%, $p < .001$), and administration in the presence of another physician (98% vs 54%, $p < .001$), and were more often self-labelled by physicians as euthanasia (96% vs 1%, $p < .001$) and reported to the FCECE (92% vs 4%, $p < .001$). Where recommended drugs were used, in 2013 compared to 2007, euthanasia requests were increasingly expressed both orally and in writing (from 67% in 2007 to 87% in 2013, $p = 0.026$) and decreasingly only orally (from 24% in 2007 to 6% in 2013, $p = 0.003$). Reporting of the case to the FCECE remained consistent at 92% in both years. Between 2007 and 2013, physicians consistently labelled cases in which non-recommended drugs were used as palliative sedation (73% vs 78%, $p = 0.791$) or alleviation of pain and symptoms (13% vs 15%, $p > 0.999$). In conclusion, guidelines and training regarding the conduct and pharmacological aspects of euthanasia may have had important effects on the euthanasia practice. However, the declining but persisting use of non-recommended drugs requires further attention.

3.1.4. Differences and commonalities in euthanasia and assisted suicide practice in Belgium, the Netherlands and Switzerland

In Chapter 6, we described and compared euthanasia and assisted suicide practices in Belgium (BE), the Netherlands (NL) and Switzerland (CH). We studied differences and commonalities across the three countries in profiles of people receiving euthanasia or assisted suicide, and physician, decision-making and clinical characteristics of euthanasia and assisted suicide cases. People who died by EAS were most commonly aged 65 or older (BE: 81%, NL: 77% and CH: 71%) and were mostly diagnosed with cancer (BE: 57% and NL: 66%). Home was the most common place of death in NL (79%), while in BE and CH more variation was found regarding to place of death. EAS requests were expressed most often both orally and in writing in BE (67%) and NL (74%),

while In CH oral requests were most common (76%). Life-shortening was frequently discussed with a colleague physician and/or the patient's relatives (BE: 86% and 81% respectively, NL: 90% and 64%, CH: 60% and 75%). Life-shortening as estimated by the attending physician was most often between one and seven days in BE (41%), one to four weeks in NL (36%), and more than four weeks in CH (41%). This suggests that, in addition to the legal context, cultural factors as well as the manner in which legislation is implemented play a role in how EAS legislation translates into practice.

3.2. Current debates regarding euthanasia

3.2.1. Involvement of palliative care services in a context of legalized euthanasia

In Chapter 7, we examined the involvement of palliative care services in the end-of-life care of people who requested euthanasia. We also studied the involvement of palliative care services and professionals in the decision-making and performance of euthanasia. Of all people who used palliative care services, 14.1% had expressed a request for euthanasia. People requesting euthanasia were more likely to have received palliative care (71%) than other people dying non-suddenly (45%) (odds ratio=2 (95% confidence interval, 1.5–2.9)), irrespective of the patient's sex, age, cause of death and place of death. The most frequently indicated reasons for non-referral to a palliative care service in those requesting euthanasia were that existing care already sufficiently addressed the patient's palliative and supportive care needs (57%) and that the patient did not want to be referred (26%). Overall, no significant differences were found between the likelihood of a euthanasia request being granted in cases where palliative care was involved in end-of-life care and those where it was not. Palliative care professionals were involved in the decision-making process and/or performance of euthanasia in 60% of all euthanasia deaths; this involvement was higher in hospitals (76%) than at home (47%) or in nursing homes (50%). In 52% of performed euthanasia cases, a palliative care professional was consulted about the euthanasia request; in 21% of cases, the physician who carried out euthanasia was part of a palliative care team; and in 7% of cases, euthanasia was performed in a palliative care unit. To conclude, in Flanders, in a context in a context of legal euthanasia, euthanasia and palliative care do not seem to be contradictory practices. A substantial proportion of people who make a euthanasia request are

seen by palliative care services, and for a majority of these, the request is then granted, often with the involvement of palliative care services in the decision-making or actual performance of euthanasia.

3.2.2. Euthanasia for people suffering from a psychiatric disorder or dementia

In Chapter 8, we investigated the prevalence of euthanasia cases with a psychiatric disorder or dementia diagnosis reported to the FCECE from implementation of the euthanasia law on September 23, 2002 until December 31, 2013. Further, we describe the clinical and decision-making characteristics of these cases. We identified 179 reported euthanasia cases with a psychiatric disorder or dementia as the sole diagnosis. These consisted of mood disorders (n=83), dementia (n=62), other psychiatric disorders (n=22) and mood disorders accompanied by another psychiatric disorder (n=12). The proportion of euthanasia cases with a psychiatric disorder or dementia diagnosis was 0.5% of all cases reported in the period 2002–2007, increasing from 2008 onwards to 3% of all cases reported in 2013 (54 cases in 2013). This increase is particularly visible in cases with a diagnosis of mood disorder. In comparison with the total number of reported cases, euthanasia for these specific patient groups remains a limited practice. The majority of euthanasia cases with a psychiatric disorder or dementia diagnosis concerned women, ranging from 58% in people with dementia to 77% in people suffering from mood disorders. All notified cases were judged to comply with the due care criteria specified in the Belgian euthanasia law by the FCECE. If, as our study suggests, people with psychiatric conditions or dementia are increasingly seeking access to euthanasia, development and implementation of practice guidelines is to be recommended if physicians are to respond adequately to these highly delicate requests.

3.2.3. Accuracy of reporting of euthanasia on death certificates

In chapter 9, we investigated what proportion of deaths in Flanders, Belgium is the result of euthanasia as estimated through the death certificate compared with an anonymous mortality follow-back survey. We also examined which patient and practice characteristics are associated with euthanasia being reported on the death certificate. In 16.2% of all euthanasia cases identified in the survey the certifying physician indicated euthanasia as cause of death on the death certificate. Identified euthanasia cases were more often certified when

barbiturates and/or muscle relaxants were used with the explicit intention of hastening death (23% covered) than when benzodiazepines (0.5% covered) or opioids (0% covered) were used for that purpose. Cases were identified as euthanasia through the survey and labelled as such on the death certificate in 24% of cases, which was more often than when labelled as ending of life from compassion (9% covered), palliative or terminal sedation (0.5% covered), intensified alleviation of pain or other symptoms (0.5% covered), or non-treatment decision (7% covered). Multivariable logistic regression controlling for sex, age, and cause of death confirmed these differences. In conclusion, death certificates substantially underestimate the frequency of euthanasia as a cause of death in Belgium and are therefore an unreliable tool for monitoring its practice. Mortality follow-back studies are thus an essential complementary instrument for examining and monitoring the practice of euthanasia more accurately.

4. Discussion of the findings

In this section, the findings of this dissertation are discussed in-depth and in relation to each other and the relevant literature.

4.1. Evolution of euthanasia in Belgium

4.1.1. The incidence of euthanasia has increased continually

A key finding of this dissertation is that the incidence of euthanasia and the absolute number of euthanasia cases have increased continuously in Belgium. Chapter 3 has shown that reported euthanasia in Belgium increased from 235 deaths in 2003 (0.2% of all deaths) to 1807 deaths in 2013 (1.7% of all deaths). The findings from Chapter 4 have shown that in Flanders the increase in euthanasia is linked to increases in both the number of euthanasia requests expressed and the proportion of requests that is granted.

In other euthanasia and/or assisted suicide permissive countries, numbers have also increased, albeit at different rates.¹⁵ Nationwide studies in the Netherlands have shown an increase in euthanasia from 1.7% in 2005 to 2.8% in 2010 and 4.5% in 2015⁶, and an increasing number of euthanasia cases is reported to the Dutch euthanasia review committees¹⁶. In Switzerland, the number of assisted suicides increased to 742 cases in 2014, 1.2% of all death and 26% more than the

year before.¹⁷ In the US, the most comprehensive figures are provided by official reports of assisted suicide practice in Oregon and Washington. For instance, figures from Oregon show that from 1998 through 2013 there has been a consistent increase of on average 14% annually in the number of deaths by assisted-suicide, and on average 36% annually from 2013 through 2015.¹⁸ From 2015 onwards figures seem to have levelled off.

In general, the rise in euthanasia in Belgium suggests an increased awareness of euthanasia as an option at the end of life and grown familiarity with the practice, both among physicians and the general public. Euthanasia is no longer considered taboo: patients seem to feel more confident to initiate discussions on euthanasia with their physician and relatives, and physicians have become more open towards the option of euthanasia. Several factors have played a role in this development. Firstly, personal experiences regarding euthanasia may have influenced granting rates. Physicians may feel more confident in granting euthanasia requests due to increased experience with the practice. Additionally, physicians may have been increasingly reassured that they would not be prosecuted when the legal criteria are adhered to. We found that physicians considerably less frequently used reasons external to the patient, such as personal objections and fear of legal consequences, as a reason for denying a euthanasia request in 2013 than in 2007 (Chapter 4). In 2015 the FCECE referred the first and up until now only euthanasia case to the public prosecutor because of nonadherence to the legal criteria.² Secondly, training and information provision may have led to increased familiarity with the euthanasia procedure. Substantial efforts have been made to inform physicians on euthanasia and the related procedures, for instance through the Life's End Information Forum which provides trained physicians who give information regarding end-of-life decisions to other physicians.^{19,20} Evidence of increased familiarity of physicians with the practice is for instance found in Chapter 5 of this dissertation, which showed that the recommended drugs for euthanasia, i.e. barbiturates and neuromuscular relaxant, are increasingly used to carry out euthanasia. Thirdly, efforts are also made to inform the general public of their options and rights at the end of life. For instance, LEIF not only provides consultation regarding end-of-life decisions for physicians, its task also includes to provide the wider public with information about euthanasia and other end-of-life issues.²¹ The increase in granting rate may be partially explained by requests being more frequently expressed by eligible patients, as patients may have become more aware of the eligibility criteria for euthanasia. Lastly, euthanasia is in Flanders frequently subject of public debate. Popular media may thus have played a significant role with regard to the increased

awareness. Especially high-profile euthanasia cases involving non-terminally ill persons have frequently received substantial media coverage the past decade.²² For instance, the death of Belgian writer Hugo Claus, who received euthanasia in an early stage of dementia, stirred up much controversy and was heavily debated in the media. In this way, people and their physicians may have become increasingly aware that not only persons with persistent and unbearable suffering due to terminal conditions such as cancer are eligible for euthanasia.

4.1.2. Expansion of euthanasia practice: euthanasia for people with psychiatric disorders, dementia or multimorbidity

We found that in the early years after the euthanasia law, euthanasia was mainly practiced for terminally ill people diagnosed with cancer. The typical patient receiving euthanasia is younger than 80 years old, well-educated, and diagnosed with cancer, as euthanasia prevalence is consistently highest in these patient populations. This has also been found in other countries allowing euthanasia and/or assisted suicide.^{15,23} In recent years, we observed an expansion towards a broader euthanasia practice in Belgium, also including persons diagnosed with psychiatric disorders and older persons, particularly those with dementia and multimorbidity (Chapters 3 & 8). While euthanasia for terminally ill persons seems to be widely accepted in Belgium, the debate has moved towards the option of euthanasia for other specific patient populations.

Euthanasia and psychiatric disorders.

One of the most controversial issues regarding the Belgian euthanasia law is that euthanasia is available for persons suffering unbearable because of psychiatric illness. In addition to Belgium, this is also possible in the Netherlands, Luxembourg and Switzerland. In other permissive countries, euthanasia and assisted suicide are limited to terminal conditions. In their biannual reports, the FCECE classifies these cases under ‘neuropsychiatric disorders’. Euthanasia cases with neuropsychiatric disorder increased significantly from 0.8% of all reported cases in 2005 to 3.9% in 2013 (Chapter 3). As this category is broader than only psychiatric disorders, we decided to investigate cases with psychiatric illness as sole diagnosis in detail.

We found that prevalence of euthanasia for unbearable suffering caused by a psychiatric disorder increased in Belgium but remains very limited (Chapter 8). The numbers have particularly risen the last few years, especially for mood

disorders to 40 cases reported in 2013. The most recent report of the FCECE mentions 63 reported euthanasia deaths in 2015 among persons with a psychiatric disorder.² A similar trend is observed in the Netherlands.^{16,24} Also, the profile of psychiatric patients in our study is generally similar to the findings from the Netherlands which showed that people receiving euthanasia in the Netherlands were mostly women and of diverse ages, with depressive disorders being the most common psychiatric problem.²⁴ As we only had information on euthanasia requests that were granted and carried out, our study did not allow to report a granting rate for requests expressed by persons with psychiatric illness. Another study conducted in Belgium among 100 consecutive people suffering from psychiatric disorders who requested euthanasia and were referred to one Belgian psychiatrist showed that, 48 were accepted and 35 were carried out.²⁵ Furthermore, this study showed that some patients decide to withdraw their euthanasia request, even those whose request was granted. It has been suggested that merely having the option of euthanasia and having their death wish being acknowledged and discussed may encourage patients to find new treatment perspectives and may alleviate their suffering, making life more bearable.^{26,27}

Concerns are frequently voiced regarding euthanasia practice for psychiatric patients.²⁸⁻³⁰ These concerns are generally related to three main issues: psychiatric patient's competence, the irremediableness of psychiatric illness, and the nature of the unbearable suffering.³⁰⁻³² Firstly, the patient's capacity to make treatment decisions may be impaired due to the mental illness. Moreover, the desire to die can be a symptom of the disease. Capacity assessment is a difficult undertaking and has been shown to be often suboptimal.³³ A study of Dutch psychiatric euthanasia cases found that physicians do not seem to set high thresholds for capacity in the assessment of the patient's decision-making capacity.³⁴ It has been acknowledged that the presence of mental illness does not preclude a patient's ability to make a competent decision. Moreover, it has been argued that the desire to die can be a rational choice, also in the presence of psychiatric illness.^{35,36} Unfortunately, in our study no information was available regarding assessment of the patient's competence. Secondly, the course of psychiatric illness is often characterized by fluctuations and response to additional treatment is uncertain. Therefore, some argue that the irremediableness of the disorder cannot be reliably determined in case of psychiatric illness.³⁷ Thirdly, the presence of unbearable suffering is a legally necessary prerequisite to be granted euthanasia. Our study found that in about three out of four psychiatric euthanasia cases only psychological suffering was reported (Chapter 8). For other cases physicians reported a combination of physical and psychological suffering. A qualitative

study among 26 psychiatric patients who requested euthanasia identified, in addition to the psychological and physical suffering related to the medical condition, intrapersonal, interpersonal, existential and societal factors play a role in the patients' suffering experience.²⁶ It is argued that suffering caused by psychiatric illness can be a legitimate reason for requesting a hastened death, as psychological suffering can be as burdensome – or even more burdensome – as suffering caused by somatic illness.³⁸ However, especially in case of psychological suffering, the legal criterion of unbearable suffering has been frequently criticized for being too vague and difficult to assess.^{39,40}

To offer physicians aid in assessing complex psychiatric euthanasia cases several instances have issued guidelines specifically aimed at euthanasia requests from persons suffering from mental illness. The Flemish Association of Psychiatrists has recently issued an advisory text in which due care requirements are formulated to make the legal provisions of the euthanasia law regarding psychiatric disorders more concrete.⁴¹ Some requirements are added to the legal criteria, such as involvement of a second psychiatrist in addition to the legally required psychiatric consultation. The advice is largely based on the Dutch guideline for issued by the Dutch Association of Psychiatrist.⁴² Additionally, also the Brothers of Charity, the Federal Advisory Committee on Bioethics and *Zorget-Icuro* – a network of 775 health care organisations in Flanders – each issued advices concerning euthanasia in persons with psychiatric illness in the last year.^{43–45}

Euthanasia and dementia.

Dementia is a degenerative condition impacting on memory and mental abilities which mainly affects older people.⁴⁶ Upon diagnosis of dementia, many people fear the mental decline that will follow, making euthanasia a possible way of thinking.⁴⁷ Our study found that, since legalisation of euthanasia, 62 persons with dementia received euthanasia, increasing from 5 persons in the period between 2002 and 2007 to 14 persons in 2013 (Chapter 8). A limitation of our data is that we do not know which stage of dementia the patients included in our analysis were in. A previous study conducted in 2007 in Flanders found that 1.3% of persons dying with dementia expressed a request for euthanasia, but none were granted.⁴⁸ It is remarkable that the increase we found in euthanasia is situated around the time (2008) Belgian writer Hugo Claus, who suffered from early Alzheimer's disease, received euthanasia. Claus' euthanasia was discussed

extensively in popular media²², which may have drawn attention to euthanasia as a possibility in case of dementia.

In Belgium, persons with early-stage or pre-dementia are eligible for euthanasia based on an actual euthanasia request provided the legal requirements are adhered to. Patients in the early stages of dementia are still capable of understanding their situation and prognosis, and of expressing their wishes. In persons with advanced dementia, decision-making capacity is impaired making euthanasia based on an actual request impossible. During the past years, several amendments to the euthanasia law have been proposed to enlarge the scope of the euthanasia law to include euthanasia for persons with severe dementia.⁴⁹ We should ask ourselves whether it is desirable for people with severe dementia to receive euthanasia based on an advance euthanasia request. The difficulty with euthanasia requests in case of dementia not only lies in assessing the voluntariness of the requests and the nature of the patient's suffering but also in choosing the right moment for carrying out the request, i.e. when the person has a period in which he or she is competent and confirms the euthanasia request.^{50,51}

The question remains how, if legalized, this will be carried out in practice. It might be useful to take a look at the Netherlands where, in contrast to the Belgian situation, euthanasia by way of an advance euthanasia directive is legally possible in case of advanced dementia. A Dutch study found that in practice physicians are not inclined to grant euthanasia in case of advanced dementia.⁵² Also, many Dutch physicians are unaware that euthanasia for mentally incompetent patient can fall under the Dutch euthanasia law, provided that all other due care requirements are adhered to.⁵³ The Dutch experience shows that, even when it is a legal possibility, euthanasia in case of advanced dementia remains an exceptional practice.⁵³ Additionally, a number of euthanasia cases have been publicised in which euthanasia in persons with severe dementia was carried out in problematic circumstances.⁵⁴

The WHO predicts dementia prevalence to double between 2015 and 2050 in Europe.⁵⁵ As the number of people suffering from dementia will continue to rise in the years to come, making euthanasia available for those who are in the advanced stages of dementia raises substantial concerns. All arguments should therefore be taken into account, with attention for the available empirical evidence on the matter.

Euthanasia and multimorbidity.

Specific attention is also needed for the group of people who were granted euthanasia because of multimorbidity, or polypathology as it is called in the FCECE's reports. Multimorbidity is defined as the presence of two or more chronic medical conditions in one individual.⁵⁶ These chronic conditions are most often degenerative in nature, can be both physical or mental in nature, and mainly affect older people. Even though the separate conditions are not necessarily fatal, combined they can cause unbearable and persistent suffering that cannot be relieved. We found an increase in reported euthanasia for persons with multimorbidity from 2.5% in 2005 to 5.9% in 2013. According to the FCECE's latest report, 10.3% of reported euthanasia cases in 2015 involved persons with multimorbidity, making it the second most frequent diagnosis after cancer.² In the Netherlands, The Dutch Regional Review Committees distinguish in their latest report between multiple disorders related to old age (*'stapelend van ouderdomsaandoeningen'*) on the one hand and combinations of disorders on the other hand. These categories accounted for 11,6% of reported euthanasia in 2016¹⁶, which is similar to the Belgian figures.

Multimorbidity is the most common chronic condition among adults, and more than half of older people are likely to experience multimorbidity.^{57,58} Taking into account the aging population and the increasing life-expectancy, the number of people with multimorbidity is expected to rise in the future. Hence, multimorbidity is increasingly being recognized as a major public health challenge in modern society.^{58,59} Additional points of concern are that multimorbidity is more prevalent in disadvantaged groups and that multimorbidity significantly increases depression.^{57,60}

Euthanasia requests from people who are tired of living have appeared on the forefront of the euthanasia debate in the last years. As the presence of a severe medical condition is required to be eligible for euthanasia, requests for euthanasia from people who are tired of living fall outside of the scope of the euthanasia law. We found that in approximately one in four euthanasia cases, tiredness of life was indicated by the attending physician as a reason for granting a euthanasia request (Chapter 4). It has to be emphasized that physicians indicated multiple reasons for granting a request, and tiredness of life was never indicated as sole reason. Our findings however suggest that physicians take tiredness of life into account in their analysis of a euthanasia and can consider it as a valid reason. It is possible that some of the generally older people suffering from multimorbidity are tired of life to some extent, and mainly request euthanasia because they feel

that their life is complete. A Dutch study found that being tired of living can play an important role in older people's requests for euthanasia.⁶¹ This emphasizes the complexity of assessing euthanasia requests expressed by this patient population and points attention to the fine line between what is possible within the boundaries of the law and what is not.

4.1.3. Euthanasia in Belgium on a slippery slope?

As was pointed out in the introduction of this dissertation (Chapter 1), the slippery slope hypothesis is one of the main arguments being invoked against legalization of euthanasia. The term has been used in the euthanasia debate for various consequences of euthanasia legislation. The substantial growth of euthanasia in general (Chapter 3 and 4), the expansion of euthanasia practice towards patient groups that were not the target audience when the law was voted (Chapter 4 and 8), and the expansion of the euthanasia law in 2014 to include competent minors^{62,63}, are frequently interpreted as proof of the slippery slope hypothesis.^{64,65} In addition to these, the intentional life-ending without explicit patient request, abuse in vulnerable patient groups or people feeling inclined to ask for euthanasia due to societal pressure are also often referred to when the slippery slope is mentioned.⁶⁶⁻⁷⁰ Considering that the slippery slope can be regarded as a container term for a number of possible consequences of euthanasia legalisation, questions can be raised whether use of the term does not stand in the way of nuanced debate.

Some see the extension of the scope of euthanasia as a positive development with the expansion of euthanasia practice towards less traditional patient groups not necessarily being problematic.^{38,50,63} According to proponents, euthanasia can be ethically acceptable and should be legally available for these patients on the condition that proper safeguards are in place. Merely the expansion of the euthanasia practice to less traditional patient populations should therefore not necessarily be cause for concern, insofar that these requests and the patients' eligibility are subjected to thorough investigation before a request is granted. Moreover, excluding these patients is seen as a form of discrimination.^{32,38} Eligibility should therefore be assessed on an individual patient-basis instead of denying an entire patient population access to euthanasia.⁷¹ According to opponents however, the legal criteria, such as the presence of unbearable suffering and the disease being without prospect for improvement, are difficult if not impossible to assess in these patient groups due to the often non-terminal

nature of the illness.^{37,72} As a consequence, it is argued that these patient populations should be excluded from euthanasia legislation.

4.2. A 'grey zone' between euthanasia and palliative sedation: overlapping end-of-life practices

Euthanasia and palliative sedation function both as last resort options for unbearable suffering at the end of life.⁷³ While palliative sedation aims to reduce or remove the consciousness of the terminally ill patient by administering sedative drugs, euthanasia is aimed at ending the patient's life by administering drugs in intentionally lethal doses at the patient's explicit request. After an initial rise in Flanders in palliative sedation to 14.5% of all deaths in 2007, its use decreased to 12.0% of all death in 2013.⁷⁴ In 17.9% of cases in 2013 life-shortening was explicitly intended or co-intended.

Our study points towards the existence of an in-between practice, or 'grey zone' in which palliative sedation is used with the intention to hasten death (Chapter 5). Previous research in Belgium and the Netherlands has already shown that palliative sedation is in practice sometimes discussed as an alternative to euthanasia.⁷⁶⁻⁸⁰ The reasons for this may be related to the patient's medical situation, for example when not all due care requirements are fulfilled. Also, the physician's personal reasons may play a role, as physicians may consider palliative sedation to be ethically preferable because of no obvious hastening of death. Lastly, restrictive institutional policy towards euthanasia may influence whether palliative sedation is used.

In the absence of a legal framework for palliative sedation in Belgium, the Flemish Palliative Care Federation issued a guideline on palliative sedation stating the conditions and manner in which palliative sedation should be carried out.⁷⁵ This guideline states that palliative sedation should be solely aimed at the relief of refractory suffering and not at hastening death (as primary or secondary aim). Further, the decision should be made with the patient or, in case the patient is incompetent, with the family.

The relation between euthanasia and palliative sedation has been extensively debated in the scientific literature. Although some argue that there is a moral difference between palliative sedation and euthanasia, others argue that both practices are morally equivalent and consider palliative sedation to be a form of 'slow euthanasia' or euthanasia in disguise.⁸¹ The issue of the relation between

palliative sedation and euthanasia is also prevalent in Belgian and Dutch medical practice.^{82,83} Although guidelines clearly distinguish between palliative sedation and euthanasia, clinicians often indicate that the distinction between the two practices may become blurred.^{78,84,85} This especially so when there is an intention (partly or explicit) to hasten the patient's death or when medication is increased disproportionately when performing palliative sedation, or when sedation is induced too early.^{78,84,86}

The existence of a grey zone between euthanasia and continuous deep sedation until death shows that the labelling of medical end-of-life decisions is inherently difficult, as medical practice is often hard to contain in a rigid classification scheme. End-of-life decision-making is no exception to this. Nevertheless, such classifications are necessary to be able to control and monitor the euthanasia practice in the broader context of medical end-of-life decision-making.

4.3. The officially reported practice of euthanasia vs euthanasia practice as identified in mortality follow-back studies

In this dissertation, two types of reported euthanasia practice in Belgium were investigated. The first is the mandatory reporting of euthanasia cases by the performing physician to the Federal Control and Evaluation Committee for Euthanasia (Chapters 3 and 8). The second is the reporting of euthanasia through the death certificate, which is not mandatory (Chapter 9). These types of reporting both seem to suffer from underreporting in comparison with the euthanasia practice as estimated through large-scale mortality follow-back studies.

4.3.1. Reporting to the Federal Control and Evaluation Committee

The euthanasia practice as reported to the FCECE made up 1.7% of all deaths in 2013 in Belgium (Chapter 3), compared to 4.6% of all deaths estimated through our mortality follow-back study in Flanders (Chapter 4). Part of this difference can be explained by the substantial discrepancy of euthanasia reporting in Wallonia compared to Flanders. Through the mortality follow-back survey we calculated that, in Flanders, 63.5% of euthanasia cases were reported to the FCECE in 2013 (Chapter 5). This is an increase compared with 2007, when

slightly more than half of all estimated cases of euthanasia were reported to the FCECE.³ However, still “only” two thirds of euthanasia cases are reported to the FCECE. Due to the broad definition of euthanasia in the mortality follow-back study, our estimation of euthanasia may be overstated. However, taking into account the most recent figures of the FCECE, it is clear that the proportion of deaths by euthanasia is still increasing and has not (yet) reached a plateau.

In the Netherlands, where a similar reporting procedure is used as the one in Belgium, the euthanasia reporting rate increased significantly from 18% in 1990 to 80% in 2005.⁸⁷ The higher reporting rate in the Netherlands may in part be explained by the fact that euthanasia was already openly practiced in the two decades before its formal legalization in 2002, and a reporting procedure has been in place since the 1990s.⁸⁸ An additional explanation is that ‘grey zone’ euthanasia cases, i.e. intentional ending of patients’ life upon explicit patient request without following the required and recommended procedures, are less prevalent in the Netherlands than in Belgium.⁸⁹ In these less clear-cut euthanasia cases, non-recommended drugs, mainly opioids and sedatives, are used instead of neuromuscular relaxants and barbiturates with the explicit intention of hastening death at the request of the dying patient. Also, these cases are generally not perceived as euthanasia by physicians but are perceived as palliative sedation or alleviation of pain and other symptoms. Consequently, as well in Belgium as in the Netherlands, these cases are not being reported to the euthanasia review committee.

The primary reason for non-reporting of euthanasia to the FCECE thus seems to be related to the type of drugs used to intentionally hasten death and the ‘grey zone’ between euthanasia and palliative sedation. If the recommended drugs for euthanasia were used, 92% of euthanasia cases were reported to the FCECE. In cases where non-recommended drugs were used reported rate was 4%. Moreover, most (93%) of the latter cases are perceived as palliative sedation or alleviation of pain and symptoms. This has also been observed in the Netherlands.^{89,90} Some physicians may overestimate the life-shortening effect of opioids and sedatives.⁹¹⁻⁹⁴ On the other hand, the use of non-recommended drugs to hasten death may point to cognitive dissonance reduction. Physicians who feel reluctant to perform euthanasia but want to help their patient who is requesting euthanasia may choose to use drugs that are normally not associated with euthanasia in order to reduce cognitive dissonance.³ A last hypothesis is that physicians may not adhere to the strict procedures of the euthanasia law because they experience these as too time consuming and burdensome.

4.3.2. Registration of euthanasia on the death certificate: implications and practical difficulties

In only 16% of cases identified as euthanasia through the mortality follow-back survey the physician had indicated euthanasia as immediate cause of death on the death certificate. There is considerable variation in the ways permissive countries deal with euthanasia and assisted suicide on the death certificate. In Belgium the euthanasia law explicitly states that death by euthanasia is to be deemed a natural death.⁹⁵ This was written into the law to avoid problems regarding payment of life insurance. In the Netherlands, death being the result of euthanasia is considered a non-natural death and is to be indicated on the Dutch death certificate by ticking a separate box for euthanasia. This might enable more accurate identification of euthanasia through death certificates. Dutch data are however not available, making comparison with the results of our study (Chapter 9) impossible. In Switzerland, in contrast to Belgium and the Netherlands, death by assisted suicide is to be indicated on the death certificate as ‘non-natural death’. As a consequence, these deaths are always investigated by a forensic team.⁹⁶

4.4. Euthanasia practice and palliative care

In the international euthanasia debate, euthanasia and palliative care are often seen as incompatible practices.⁹⁷⁻⁹⁹ The current situation in Belgium seems to contradict this view. We found that palliative care services are frequently involved in the end-of-life care of people requesting euthanasia and that health professionals working in palliative care are often involved in the euthanasia procedure. Further evidence for the integration of palliative care and euthanasia is also found in our study of euthanasia cases reported to the FCECE. In 2013, in one out of ten reported cases the consulted physician was specialized in palliative care and in four out of ten cases palliative care teams were consulted about the patient’s euthanasia request even though it is not required to do so. These findings are in line with previous studies in Belgium which found that euthanasia frequently occurs in the context of multidisciplinary end-of-life care¹⁰⁰ and that Belgian physicians who are likely to be involved in end-of-life care generally accept euthanasia as part of good end-of-life care.¹⁰¹

More precisely, we found that palliative care services were involved in the end-of-life care in 71% of those who requested euthanasia. In Oregon and Washington, in approximately 90% of assisted suicides the patient was enrolled

in hospice care. This higher involvement is most likely linked to the fact that only person with terminal illness who have less than six months to live are eligible for assisted suicide in Oregon and Washington. It would not be desirable that all people requesting and receiving euthanasia would receive specialist palliative care (the so-called palliative filter), as not all people who request euthanasia would necessarily benefit from involvement of specialist palliative care services. In more than half of deaths by euthanasia without referral to palliative care, the patient was not referred because the care already sufficiently addressed the patient's palliative and supportive care needs. Additionally, we found that in about one in four people who requested euthanasia and were not referred to palliative care services, the reason for non-referral was that the patient refused it. This corroborates the findings from a previous Dutch study.¹⁰² It is however to be encouraged that patients are informed about other options than euthanasia and that palliative care options are sufficiently explored.

Palliative care being frequently involved in euthanasia is not a surprising finding for those who are acquainted with the Belgian euthanasia practice. The palliative care movement and euthanasia activism gradually developed side by side since the early 1980s, culminating into the enactment of laws on euthanasia and palliative care in 2002.¹⁰³ In this, the federation was the first professional palliative care organisation worldwide to acknowledge euthanasia practice within a palliative care context, which has been termed “integral palliative care”.^{103–105} The Federation of Palliative Care Flanders is unique in its positive stance towards inclusion of euthanasia practice in palliative care practice. Professional palliative care organisations elsewhere either do not take a position in favour or against assisted death (so-called studied neutrality) or do take the position against assisted death.¹⁰⁶

It is being increasingly acknowledged that palliative care may not be able to alleviate all people's suffering, despite availability of optimal palliative care.¹⁰⁷ Our study found that 14% of people who received palliative care had expressed a euthanasia request. Such requests are however not unique to the context of legalised euthanasia. Studies have shown that wishes to hasten death are also prevalent in palliative care settings in countries without a legal framework for euthanasia or assisted suicide.^{108–110} Palliative care professionals are thus frequently confronted with people who want to hasten their death, regardless of the existence of euthanasia or assisted suicide legislation. This can be expected taking into account that open discussion of death and dying is an important element of palliative care.^{111,112}

5. Implications and recommendations

As a result of what we found in our studies, a number of recommendations can be formulated to improve euthanasia practice and future monitoring of the practice. In this section, several implications and recommendations for policy, practice and future research are identified.

5.1. Implications and recommendations for policy and practice

When the euthanasia law came into force in Belgium, adequate control over carefulness of the practice was considered an important prerequisite for effective legislation. Based on the findings of this dissertation there is still quite some room for improvement of societal control over euthanasia practice. Palliative sedation is sometimes performed with the intention to hasten the patient's death (cfr. slow euthanasia). Societal control over euthanasia practice might be improved by installing an additional control system for monitoring of palliative sedation practice. Registration of palliative sedation, with information on procedures used and the decision-making process for palliative sedation may provide a more complete picture of euthanasia practice especially with regard to the grey area between palliative sedation and euthanasia. The Brussels University Hospital has recently implemented registration of all deaths in which the patient was continuously sedated until death.¹¹³ Registration of palliative sedation and the use of standardized procedures may improve carefulness of both palliative sedation and euthanasia practice.

Also, the registration form used for the mandatory notification to the FCECE can be improved by including additional questions, such as (palliative) treatment options discussed with the patient, (palliative) treatment options used, date of (first) request for euthanasia, involvement of LEIF physicians (either reporting physician or consulted physicians), time between drugs administration and death, or possible complications during the euthanasia procedure or performance. These issues are relevant elements to assess compliance with the due care criteria for euthanasia.

For a more complete certification of euthanasia on death certificates consideration may need to be given to modifying the death certificate form and providing clear guidelines to physicians about whether and how they should record euthanasia on the death certificate. Asking physicians to indicate on the

death certificate whether or not death was caused by euthanasia, as done in the Netherlands, may improve registration of euthanasia through death certificates.

Considering the complexity of assessment of euthanasia requests expressed by people with psychiatric illness, additional monitoring through the appointment of a separate subcommittee to review and control these specific cases or through a priori control of euthanasia requests based on unbearable suffering resulting from a psychiatric disorder is recommended. This procedure may not be desirable for terminally ill people. For people with nonterminal illness however, there should be enough time for prior review by a multidisciplinary committee including psychiatrists, experts in euthanasia and end of life care, and ethicists.

Some findings of this dissertation point to a possible impact of guidelines and training for physicians on euthanasia practice. Therefore, continuation and further expansion of initiatives aimed at improving health professionals' skills regarding the euthanasia procedure, euthanasia performance and other medical end-of-life decisions is recommended. Trainings might for example, in addition to physicians and nurses, also be aimed at psychologists and social workers active in the end-of-life care of people requesting euthanasia. However, despite the rise in compliance with due care criteria and recommended procedures, we found that physicians still use drugs that are advised against, mainly opioids, to hasten death upon explicit patient request. These cases remain unreported to the Euthanasia Review Committee because physicians do not consider them to be euthanasia. Further education of physicians on euthanasia procedures and the effects and side effects of opioids and sedatives is needed to avoid euthanasia being performed in a way that may be harmful to patients and their relatives, and beyond societal control.

Euthanasia can only be considered as an acceptable choice if supply of and access to palliative care are guaranteed. At the moment, there are no indications that this would not be the case in Belgium, but nonetheless further expansion of palliative care is a necessary. Considering palliative care professionals' extensive experience regarding end-of-life issues, it is to be encouraged that they are involved in euthanasia practice. Attention should however be paid that palliative care providers are not overburdened by time-consuming euthanasia requests and the accompanying intensive procedures and that other palliative care needs are sufficiently met. In view of the expanding euthanasia practice and the desirability of palliative care professionals being involved in the clearing of euthanasia requests, the capacity of palliative care services need to be increased. Seeking professional support, such as palliative care professionals and LEIF physicians

and nurses, in case of euthanasia requests should be encouraged. It is to be recommended that experts on palliative care and end-of-life care are consulted, especially when it concerns a complex case (multimorbidity, dementia, psychiatric illness, tiredness of life).

5.2. Implications and recommendations for future research

The findings of this dissertation have identified several new areas of research and themes that should be further studied in detail. The underreporting of euthanasia impedes societal control and transparency of the euthanasia practice. Large-scale anonymous surveys, such as the one used in this dissertation, thus seem to be indispensable tools to adequately monitor and evaluate euthanasia practice. Moreover, to gain deeper insight into euthanasia practice and observed trends, this large-scale quantitative research should be supplemented by complementary qualitative studies. In this way, certain striking results that were found in this dissertation can be further explored. For instance, physicians' motivations for using non-recommended drugs to intentionally hasten death and possible complications associated with non-recommended euthanasia practice should be explored in detail.

No population-based death certificate studies on euthanasia practice and decision-making have been conducted in Wallonia, the French-speaking part of Belgium. While roughly 40% of the Belgian population is French-speaking, only 20% of euthanasia cases reported to the FCECE were reported in French.² Whether this imbalance is caused by either less euthanasia performance among French-speaking physicians, or less reporting of euthanasia by French-speaking physicians cannot be determined, as a mortality follow-back survey using death certificates allowing an estimation of granting rates has not yet been performed in Wallonia. Considering the imbalance in reported euthanasia cases and differing attitudes towards euthanasia of Walloon physicians compared to Flemish physicians^{101,114-117}, more studies of euthanasia practice in Wallonia are in order. A death certificate study similar to the one conducted in Flanders should therefore also be performed in Wallonia. Such a study might provide important further insight into the underlying reasons for differences in euthanasia practice between Flanders and Wallonia.

Euthanasia in patient groups that are considered vulnerable, mainly people with psychiatric disease and older people, remains a highly controversial issue. In this

dissertation increases in euthanasia practice were found among these patient populations. Taking into account the complexity of assessing these euthanasia requests, a deeper understanding of euthanasia practice for these people is needed. Therefore, research is needed focussing on euthanasia procedures and outcomes in vulnerable population groups, including the reasons why they request euthanasia.

Cross-national comparison of euthanasia and assisted suicide practice has become increasingly relevant as the public debate on medically assisted death has boomed worldwide.^{118,119} In this dissertation a first important step was taken towards robust cross-national comparison of assisted death practices. This study was limited to permissive countries in Europe. More research is therefore needed both in permissive countries outside of Europe, i.e. in North-America, Australia and Colombia, and non-permissive countries. In addition to incidences of different medical end-of-life practices including euthanasia and assisted suicide, attitudes towards these practices should be further studied in order to gain more insight into differing practices between countries.

This dissertation focussed on the physician's perspective. In order to gain a more complete picture of euthanasia practice in Belgium, more research is needed including the perspectives and experiences of patients, patient's relatives and professional caregivers other than physicians, such as nurses and psychologists. Specific current knowledge gaps include how patients and their relatives experience the euthanasia procedure, the impact of the euthanasia decision-making process and performance on bereaved relatives and professional caregivers other than physicians, and bereavement care needs among relatives of people who died by euthanasia. It is to be recommended that a combination of quantitative and qualitative research methods is used to study these issues.

6. Conclusion

This dissertation has added to the understanding of Belgian euthanasia practice by studying trends in euthanasia practice and by providing empirical evidence regarding certain issues that have been subject of (international) debate. We found a substantial increase in the number and proportion of deaths by euthanasia, which is related to increases in both the number of euthanasia requests being expressed and the proportion of requests being granted. Moreover, the legal possibilities of euthanasia legislation are being more broadly

explored and seem to have become more broadly accepted. While physicians have increasingly used the established procedures for euthanasia, the declining but persisting use of non-recommended drugs, mainly opioids, for hastening death on patient request requires attention. We also found that euthanasia and assisted suicide practice characteristics may vary considerably in countries with legal euthanasia and assisted suicide. Furthermore, euthanasia and palliative care do not seem contradictory practices in Flanders, as palliative care professionals are frequently involved in end-of-life care for people requesting euthanasia and in euthanasia performance. Lastly, death certificates in Flanders substantially underestimate the frequency of euthanasia as cause of death. These findings can help inform the debate on allowing euthanasia or assisted suicide for people with unbearable suffering.

This thesis underlined the importance of detailed monitoring of euthanasia practice. To meet this, it is to be recommended that monitoring by the FCECE is supplemented by thorough empirical research into euthanasia and related medical end-of-life practices, including all Belgian language communities.

What does the future hold for euthanasia and assisted suicide? One of the questions resulting from this dissertation remains whether the boundaries of the euthanasia law will be stretched further and, if so, how far they can be stretched. Overall, a tendency can be observed towards broadening the law to include other patient populations. In this regard, several new bills have aimed to extend the euthanasia law to include persons with severe dementia. Up until now, none of those have passed, but it cannot be excluded that this will happen in the future. Additionally, in both Belgium and the Netherlands, debate is growing regarding euthanasia for people who are tired of life and consider their life to be completed.

Several other important questions remain: How will euthanasia and assisted suicide further develop, as well in permissive countries as outside these jurisdictions? Is there a plateau for euthanasia in permissive countries or will prevalence continue to increase? To what extent will the prevalence of assisted death legislation further expand? To what extent might euthanasia legislation in permissive countries be expanded? Which other jurisdictions/countries will legalise the practice? Also, for countries considering legalization of euthanasia or in the process of legalization, the important question is not only whether to allow euthanasia or not, but also: for whom?

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Samenvatting van de belangrijkste bevindingen

1. Inleiding

Als gevolg van het groeiende aantal overlijdens dat voorafgegaan wordt door langdurige en progressieve ziektes en de toenemende invloed van medisch-technologische ingrepen hebben zich heel wat veranderingen voorgedaan de laatste decennia in de zorg rond het levenseinde. Medische levenseindebeslissingen zijn hierdoor een belangrijk onderdeel geworden van de hedendaagse medische praktijk. Dit kan onder meer beslissingen rond euthanasie inhouden, i.e. het toedienen van dodelijke middelen met de intentie om het leven van de patiënt te beëindigen op diens uitdrukkelijk verzoek.

Sinds 2002 kunnen artsen in België legaal ingaan op de vraag naar euthanasie van een patiënt indien voldaan is aan een aantal in de wet omschreven zorgvuldigheidsvoorwaarden en procedures. Zo moet de patiënt de vraag naar euthanasie vrijwillig, overwogen en herhaald stellen en bovendien moet de vraag neergeschreven worden. Verder mag het verzoek niet tot stand gekomen zijn als gevolg van externe druk. De patiënt moet zich in een medisch uitzichtloze toestand bevinden van aanhoudend en ondraaglijk fysiek of psychisch lijden dat niet gelenigd kan worden. Dit lijden moet het gevolg zijn van een ernstige en ongeneeslijke aandoening die veroorzaakt werd door ziekte of ongeval.

Naast deze materiële vereisten zijn er ook een aantal procedurele vereisten. Zo moet de behandelende arts een collega raadplegen over de ernstige en ongeneeslijke aard van de aandoening. De geraadpleegde arts moet hiertoe de patiënt onderzoeken en het medisch dossier inkijken en een verslag opstellen van zijn bevindingen. Deze arts moet onafhankelijk zijn van zowel de patiënt als van de behandelende arts. Indien de arts van oordeel is dat de patiënt niet zal overlijden binnen afzienbare tijd, moet hij een derde onafhankelijke arts raadplegen over het verzoek. De derde arts moet een psychiater zijn of specialist in de aandoening in kwestie. Na uitvoering van de euthanasie moet de uitvoerende arts dit melden aan de Federale Controle- en Evaluatiecommissie Euthanasie die vervolgens nagaat of aan de wettelijke vereisten werd voldaan.

Gezien het omstreden karakter van euthanasie blijft de (internationale) bezorgdheid over de Belgische levenseindepraktijk groot. De incidentie van medische levenseindepraktijken zoals euthanasie, de sociodemografische kenmerken (bijvoorbeeld of er al dan niet risicogroepen of kwetsbare groepen zijn) en besluitvormingskenmerken (bijvoorbeeld betrokkenheid van patiënt, familie en andere zorgverleners bij de besluitvorming) moeten opgevolgd worden. Trends in levenseindepraktijken verschaffen inzicht in ontwikkelingen

in de kwaliteit van deze praktijken en maken het mogelijk om praktische en ethische prioriteiten voor de medische praktijk aan het levenseinde te identificeren.

Met het onderzoek voorgesteld in dit proefschrift willen we representatieve cijfers geven over de prevalentie en de belangrijkste karakteristieken van de Belgische euthanasiepraktijk. Verder willen we ook een bijdrage leveren aan het euthanasiedebat door het verschaffen van empirische gegevens.

2. Onderzoeksvragen

Vier onderzoeksvragen behandelden het voorkomen van euthanasie en trends over de tijd:

- 1 Is er een verandering in de melding van euthanasie en in de kenmerken van euthanasie over de jaren heen?
- 2 Wat zijn de trends in het verzoeken van euthanasie en het inwilligen van euthanasieverzoeken?
- 3 Wat zijn de veranderingen over de tijd in middelen die gebruikt worden bij de uitvoering van euthanasie en hoe verschillen de kenmerken van euthanasiegevallen naargelang de gebruikte middelen?
- 4 Wat zijn de gelijkenissen en verschillen in de kenmerken van euthanasie en hulp bij zelfdoding in Vlaanderen, Nederland en Zwitserland?

Drie onderzoeksvragen behandelden enkele belangrijke topics in het huidige euthanasiedebat:

- 5 In welke mate is palliatieve zorg betrokken in de euthanasiepraktijk?
- 6 Hoe evolueerde het aantal gemelde euthanasiegevallen met een psychiatrische aandoening of dementie als diagnose en wat zijn de demografische, klinische en besluitvormingskenmerken van deze gevallen?
- 7 In welke mate wordt euthanasie geregistreerd als oorzaak van overlijden op overlijdensattesten?

3. Methodes

We gebruikten twee verschillende methodes om de onderzoeksvragen te beantwoorden. Ten eerste analyseerden we de databestanden van de Federale Controle- en Evaluatiecommissie voor Euthanasie (FCECE) met geanonimiseerde gegevens van alle gemelde euthanasiegevallen. Ten tweede maakten we gebruik van een vragenlijststudie bij de attesterende artsen van een representatieve steekproef van overlijdensattesten in Vlaanderen. In hoofdstuk 2 van dit proefschrift worden de gebruikte methodes uitvoerig belicht. Een grondige bespreking van de sterktes en zwaktes van beide methodes is te vinden in het discussiehoofdstuk (Hoofdstuk 10).

3.1. Databestanden van de Federale Controle- en Evaluatiecommissie voor Euthanasie

Zoals vastgelegd in de Belgische euthanasiewet moeten alle gevallen van euthanasie gemeld worden bij de FECEC zodat deze kan nagaan of de euthanasie werd uitgevoerd volgens de voorwaarden en procedures voorgeschreven door de euthanasiewet. Om onderzoeksvragen 1 en 6 te beantwoorden bestudeerden we de databestanden van de FCECE met geanonimiseerde gegevens over alle gemelde euthanasiegevallen in België sinds de implementatie van de euthanasiewet op 22 september 2002 tot en met 31 december 2013 (N=8752). De gegevens werden door de FCECE verzameld via een gestandaardiseerd registratieformulier.

3.2. Vragenlijststudie bij artsen gebruik makend van overlijdensattesten

Om onderzoeksvragen 2, 3, 4, 5 en 7 te beantwoorden maakten we gebruik van de gegevens die in 2013 verzameld werden in het kader van een onderzoek naar medische beslissingen aan het levenseinde in Vlaanderen. Deze methode is gebaseerd op het gebruik van overlijdensattesten. Hiervoor werd de medewerking verkregen van het Vlaams Agentschap Zorg en Gezondheid, de instantie die instaat voor het verwerken van Vlaamse overlijdensattesten.

Er werd een grote en representatieve steekproef getrokken van alle overlijdensattesten in Vlaanderen van personen ouder dan één jaar. Deze

steekproef telde 6871 overlijdens. De artsen die de geselecteerde overlijdensattesten hadden geattesteerd werden aangeschreven met de vraag om deel te nemen aan het onderzoek door een gestandaardiseerde vragenlijst in te vullen over de medische beslissingen genomen aan het levenseinde van de betrokken overledenen, over het besluitvormingsproces, en over de verstrekte zorg aan het levenseinde. De sociodemografische gegevens van de overledenen alsook hun doodsoorzaak werden achteraf op anonieme wijze gekoppeld aan de antwoorden op de vragenlijsten.

De anonimiteit van de deelnemende artsen en patiënten werd gegarandeerd via een rigoureuze procedure voor dataverzameling waarin het verzenden en ontvangen van de vragenlijsten, en het verwerken van de gegevens ruimtelijk werden gescheiden en telkens door verschillende partijen werden uitgevoerd. Een beëdigde advocaat moest erop toezien dat geen enkele ontvangen vragenlijst kon gelinkt worden aan een bepaalde arts of patiënt. De anonimiteitsprocedure kreeg een positief advies van de Ethische Commissie van UZ Brussel, van de Nationale Raad van de Orde der Artsen, en van de federale Privacycommissie.

De gehanteerde methode is zeer betrouwbaar en werd reeds herhaaldelijk in verschillende landen gebruikt, waaronder Nederland en Zwitserland. Het is de vierde keer dat deze methode in Vlaanderen gebruikt werd, wat het mogelijk maakt om veranderingen over de tijd te bestuderen.

4. Belangrijkste bevindingen

De resultaten van de uitgevoerde studies en de antwoorden op de onderzoeksvragen van dit proefschrift worden hier samengevat.

4.1. Trends in de euthanasiepraktijk

4.1.1. Trends in de melding van euthanasiegevallen aan de Federale Controle- en Evaluatiecommissie Euthanasie

Om maatschappelijke controle en evaluatie van de euthanasiewet mogelijk te maken, werd een verplichte meldingsprocedure geïncorporeerd in de Belgische euthanasiewet. In hoofdstuk 3 beschreven we trends in patiëntkenmerken, besluitvormingskenmerken en uitvoeringskenmerken van euthanasie met behulp

van de database van alle euthanasiegevallen (N=8752) gerapporteerd aan de FCECE tussen 1 januari 2003 en 31 december 2013.

We vonden dat het aantal gemelde euthanasiegevallen jaarlijks steeg, van 235 gevallen (0,2% van alle sterfgevallen) in 2003 tot 1807 gevallen (1,7% van alle sterfgevallen) in 2013. Het percentage euthanasie steeg aanzienlijk bij personen van 80 jaar of ouder, bij personen die overlijden in een woonzorgcentrum, bij mensen met een andere aandoening dan kanker en bij personen die niet binnen afzienbare tijd zouden overlijden. In 2013 betroffen de gemelde euthanasiegevallen meestal personen met kanker (69% van de euthanasiegevallen gemeld in 2013) en personen jonger dan 80 jaar (65% van de euthanasiegevallen gemeld in 2013). Palliatieve teams werden steeds vaker geraadpleegd over euthanasieverzoeken, bovenop de wettelijk vereiste consultatie(s) in het kader van een euthanasie-uitvoering. Van de gevallen die in het Nederlands werden gemeld, daalde het aandeel waarin de persoon naar verwachting binnen afzienbare tijd zou sterven van 94% in 2003 tot 84% in 2013, en palliatieve teams werden in toenemende mate geraadpleegd over het euthanasieverzoek (van 34% in 2003 tot 43% in 2013). Deze trends waren niet zichtbaar euthanasiegevallen die in het Frans gemeld waren.

Door de waargenomen stijgingen bij niet-terminale patiënten en ouderen toont onze analyse het belang aan van nauwkeurige monitoring van ontwikkelingen in de euthanasiepraktijk.

4.1.2. Trends in het verzoeken van euthanasie en het inwilligen van euthanasieverzoeken

Niet elk euthanasieverzoek leidt uiteindelijk tot euthanasie. Patiënten kunnen hun verzoek intrekken, kunnen overlijden vooraleer een beslissing genomen wordt, of het verzoek kan geweigerd worden. In hoofdstuk 4 rapporteerden we de resultaten van de grootschalige vragenlijststudie bij artsen gebruik makend van overlijdensattesten met betrekking tot euthanasieverzoeken en inwilliging van deze verzoeken. We vergeleken deze met de resultaten van een identiek onderzoek uitgevoerd in 2007.

We vonden dat het aandeel van euthanasie steeg van 1.9% van de overlijdens in 2007 naar 4.6% van de overlijdens in 2013, als gevolg van een stijging in het aantal euthanasieverzoeken en een stijging in het aantal ingewilligde euthanasieverzoeken. De incidentie van euthanasieverzoeken steeg van 3.4% van de overlijdens in 2007 naar 5.9% van de overlijdens in 2013 en het aandeel van

uitgevoerde verzoeken steeg van 55% naar 77%. De meest uitgesproken stijgingen in euthanasieverzoeken zagen we bij personen die 80 jaar of ouder waren (van 2% naar 5%), hoger opgeleiden (van 5% naar 13%) en personen met een diagnose van cardiovasculaire aandoeningen (0.8% tot 3%). De grootste stijgingen in ingewilligde verzoeken zagen we bij vrouwen (van 46% naar 76%) en personen van 80 jaar of ouder (38% tot 75%), met een lager opleidingsniveau (van 35% naar 69%) en overleden in een woonzorgcentrum (van 23% naar 68%).

In 2013 waren de belangrijkste redenen voor het verlenen van een euthanasieverzoek volgens de artsen het verzoek van de patiënt (88%), fysiek en/of psychisch lijden (87%) en het gebrek aan vooruitzichten op verbetering van de toestand van de patiënt (78%). De belangrijkste redenen om een euthanasieverzoek niet uit te voeren waren dat de patiënt vóór de beslissing overleed (59%), het verzoek werd ingetrokken (18%) en niet aan de wettelijke criteria was voldaan (20%). Het percentage gevallen waarin de arts meldde dat het verzoek niet werd uitgevoerd om redenen niet gerelateerd aan de patiënt, zoals instellingsbeleid, principiële bezwaren tegen levensbeëindiging of vrees voor juridische gevolgen, daalde van 23% in 2007 naar 2% in 2013.

Het aandeel van overlijdens waarbij een verzoek tot euthanasie was geuit is aanzienlijk toegenomen in verschillende patiëntengroepen en, na 11 jaar ervaring met de praktijk, zijn artsen meer bereid om deze verzoeken in te willigen.

4.1.3. Veranderingen over de tijd in de middelen die gebruikt worden om euthanasie uit te voeren

Volgens richtlijnen is een overdosis barbituraten eventueel gevolgd door een spierverslapper de aangewezen methode voor de uitvoering van euthanasie. Andere middelen zoals opiaten en benzodiazepines worden afgeraden gezien hun onzeker dodelijk effect en mogelijke negatieve bijwerkingen. In hoofdstuk 5 gingen we aan de hand van de vragenlijststudie bij artsen na welke middelen gebruikt worden voor euthanasie en hoe dit evolueerde over de tijd.

De aangewezen middelen voor euthanasie werden in toenemende mate gebruikt, we vonden meer bepaald een stijging van 12% van alle overlijdens door euthanasie in 1998 tot 55% in 2007 en 67% in 2013. We vergeleken ook de karakteristieken van euthanasie uitgevoerd met aanbevolen middelen en euthanasie uitgevoerd met niet-aanbevolen middelen in 2013. Bij euthanasiegevallen met aanbevolen middelen was er vaker zowel een mondeling als schriftelijk euthanasieverzoek (87% vs. 14%), consultatie van een collega-arts

(94% vs. 69%), de euthanasie werd vaker uitgevoerd in aanwezigheid van een arts (98% vs. 54%), werd vaker door de arts beschouwd als euthanasie (96% vs. 1%) en gemeld aan de FCECE (92% vs. 4%). Tussen 2007 en 2013 werden euthanasiegevallen uitgevoerd met niet-aanbevolen middelen consistent door de arts beschouwd als palliatieve sedatie (73% vs. 78%) of pijn- en symptoombestrijding (13% vs. 15%).

Artsen in Vlaanderen gebruiken steeds meer de aanbevolen middelen voor euthanasie. Dit suggereert dat richtlijnen en training met betrekking tot gedrag en farmacologische aspecten van euthanasie een belangrijk effect hebben gehad op de euthanasiepraktijk. Het aanhoudende gebruik van niet-aanbevolen middelen vereist echter de nodige aandacht, gezien deze gevallen niet gemeld worden aan de FCECE omdat ze door de artsen niet beschouwd worden als euthanasie.

4.1.4. Verschillen en overeenkomsten in euthanasie en hulp bij zelfdoding in België, Nederland en Zwitserland

Euthanasie en hulp bij zelfdoding zijn legaal in Nederland en België terwijl enkel hulp bij zelfdoding wettelijk mogelijk is in Zwitserland. Gezien het groeiende aantal landen dat wetgeving overweegt rond euthanasie en/of hulp bij zelfdoding, is het relevant om een beschrijving te geven van de bestaande praktijk in landen waar reeds wetgeving is. Hoofdstuk 6 had daarom als doel de praktijk van euthanasie en hulp bij zelfdoding in België (BE), Nederland (NL) en Zwitserland (CH) te beschrijven en vergelijken. Dit deden we aan de hand van een identieke vragenlijststudie bij artsen in de drie landen.

We bestudeerden 349 sterfgevallen door euthanasie en hulp bij zelfdoding in BE (4,6% van alle sterfgevallen), 851 in NL (4,6% van alle sterfgevallen) en 65 in CH (1,4% van alle sterfgevallen). Mensen die stierven door euthanasie en hulp bij zelfdoding waren meestal 65 jaar of ouder (BE: 81%, NL: 77% en CH: 71%) en werden meestal gediagnosticeerd met kanker (BE: 57% en NL: 66%). Thuis was de meest voorkomende plaats van overlijden in NL (79%), terwijl in BE en CH meer variatie werd gevonden met betrekking tot de plaats van overlijden. Verzoeken voor euthanasie en hulp bij zelfdoding werden meestal zowel mondeling als schriftelijk uitgedrukt in BE (67%) en NL (74%), terwijl in CH mondelinge verzoeken het meest gebruikelijk waren (76%). Levensverkorting werd vaak besproken met een collega-arts en/of familieleden van de patiënt (BE: respectievelijk 86% en 81%, NL: 90% en 64%, CH: 60% en 75%).

Levensverkorting zoals geschat door de behandelend arts was meestal tussen één en zeven dagen in BE (41%), één tot vier weken in NL (36%) en meer dan vier weken in CH (41%).

Er is aanzienlijke variatie in de praktijk van euthanasie en hulp bij zelfdoding in de bestudeerde landen, zelfs tussen landen met een grotendeels vergelijkbare wetgeving. Dit suggereert dat, naast de juridische context, culturele factoren, evenals de manier waarop de wet geïmplementeerd wordt, een rol spelen bij de vertaling van euthanasie en hulp bij zelfdoding wetgeving naar de praktijk.

4.2. Belangrijke topics in het huidige euthanasiedebat

4.2.1. De betrokkenheid van palliatieve zorg in de euthanasiepraktijk

In het internationale euthanasiedebat wordt vaak gesteld dat euthanasie onverenigbaar is met goede palliatieve zorg. In België, waar euthanasie in 2002 werd gelegaliseerd, heeft de Federatie voor Palliatieve Zorg Vlaanderen het standpunt onderschreven dat euthanasie kan ingebed zijn in palliatieve zorg. In hoofdstuk 7 bestudeerden we aan de hand van de vragenlijststudie bij artsen de betrokkenheid van palliatieve zorg in de euthanasiepraktijk in Vlaanderen.

We vonden dat 14% van de personen die gebruik maakten van een dienst palliatieve zorg (i.e. een palliatieve thuiszorgequipe, een palliatief supportteam in een ziekenhuis, een palliatieve eenheid of een palliatieve referentiepersoon in een woonzorgcentrum) een euthanasieverzoek uitte. Personen met een euthanasieverzoek hadden dubbel zoveel kans om palliatieve zorg te krijgen (71% kreeg palliatieve zorg) dan personen van wie het overlijden verwacht werd zonder euthanasieverzoek (43% kreeg palliatieve zorg).

De meest frequente redenen voor de artsen om geen palliatieve zorg in te schakelen bij personen met een euthanasieverzoek waren dat de palliatieve en ondersteunende zorgnoden al voldoende werden opgenomen door de bestaande zorg (57%) en dat de patiënt geen palliatieve zorg wilde (26%). De kans dat een euthanasieverzoek werd ingewilligd verschilde niet naargelang de betrokkenheid van palliatieve zorgdiensten in de levenseindezorg. In 60% van de overlijdens door euthanasie was een palliatieve zorgverlener betrokken bij het besluitvormingsproces en/of de uitvoering van euthanasie. Deze betrokkenheid was hoger in ziekenhuizen (76%) dan thuis (47%) of in woonzorgcentra (50%).

Deze bevindingen tonen aan dat de euthanasiepraktijk en de palliatieve zorgpraktijk elkaar allerminst uitsluiten in Vlaanderen. Palliatieve zorgverleners

worden frequent geconfronteerd met euthanasieverzoeken en euthanasie-uitvoeringen.

4.2.2. Euthanasie bij personen met een psychiatrische aandoening of dementie

Euthanasie voor personen met een psychiatrische aandoening of dementie is legaal in België onder strikte voorwaarden maar blijft een controversiële praktijk. In hoofdstuk 8 gingen we aan de hand van de anonieme gegevens die de Federale Controle en Evaluatiecommissie Euthanasie verzamelt als onderdeel van de wettelijk verplichte registratieprocedure voor euthanasie na hoe vaak euthanasie bij personen met een psychiatrische aandoening of dementie voorkomt en welke evoluties er plaatsvonden in deze praktijk sinds de euthanasiewet.

We vonden dat tussen 2002 en 2013 179 euthanasietoepassingen bij personen met een psychiatrische aandoening of dementie gemeld werden bij de Commissie. Het ging om personen met een stemmingsstoornis (46%), dementie (35%), een andere psychiatrische aandoening dan een stemmingsstoornis (12%) of een stemmingsstoornis met een bijkomende psychiatrische stoornis (7%). In 77% van de euthanasietoepassingen bij personen met een stemmingsstoornis ging het om een vrouw en in 39% van deze euthanasiegevallen betrof het iemand van 80 jaar of ouder. Het aandeel van euthanasie bij personen met een psychiatrische aandoening of dementie steeg van 0.5% van alle gemelde gevallen van 2002 t.e.m. 2007 naar 3% van alle gevallen die gemeld werden in 2013.

Euthanasie bij personen met een psychiatrische stoornis of dementie gaat dus in stijgende lijn, maar blijft laag in verhouding tot het totale aantal euthanasietoepassingen, die meestal betrekking hebben op personen met een terminale, somatische aandoening zoals kanker.

4.2.3. Het rapporteren van euthanasie op overlijdensattesten

Overlijdensattesten vormen de grootste bron van informatie over de doodsoorzaak en zouden dus ook geschikt kunnen zijn om na te gaan hoe vaak mensen door euthanasie overlijden in landen waar euthanasie wettelijk mogelijk is. In hoofdstuk 9 gingen we aan de hand van de vragenlijststudie bij de attesterende artsen van een representatieve steekproef van overlijdensattesten in Vlaanderen na in welke mate euthanasie geregistreerd wordt op overlijdensattesten.

Aan de hand van overlijdensattesten werd 0.7% van alle overlijden geïdentificeerd als een overlijden door euthanasie, terwijl via de vragenlijststudie 4.6% van alle overlijdens geïdentificeerd werd als een overlijden door euthanasie. Slechts 16% van de overlijdens door euthanasie geïdentificeerd door de vragenlijststudie was ook als euthanasie geregistreerd op het overlijdensattest. Euthanasie werd vaker vermeld op het overlijdensattest indien directe oorzaak van overlijden wanneer de onderliggende doodsoorzaak kanker was (14% van euthanasiecases geïdentificeerd door de vragenlijst was gerapporteerd op het overlijdensattest), een neurologische aandoening (22%) of beroerte (28%) dan in het geval van een cardiovasculaire aandoening (7%). Indien de aanbevolen middelen voor euthanasie werden gebruikt of indien de arts zelf de handeling als euthanasie bestempelde, werd euthanasie in 24% van de gevallen vermeld als oorzaak van overlijden op het overlijdensattest.

Overlijdensattesten onderschatten de frequentie van euthanasie als doodsoorzaak in België aanzienlijk en zijn daarom ontoereikend om de toepassing van euthanasie te monitoren. Grootschalige representatieve vragenlijststudies zijn essentiële aanvullende instrumenten om de euthanasiepraktijk te bestuderen en nauwkeurig op te volgen.

5. Discussie en aanbevelingen

Hoofdstuk 10 van dit proefschrift beschrijft de sterktes en beperkingen van de twee onderzoeksmethodes die gebruikt werden. Verder worden in dit hoofdstuk ook de belangrijkste resultaten van de studies samengevat en geïnterpreteerd en worden aanbevelingen gegeven voor beleid, praktijk en verder onderzoek. Hieronder worden enkele belangrijke discussiepunten en aanbevelingen kort beschreven.

5.1. De evolutie van euthanasie in België

De incidentie van euthanasie ten opzichte van het totale aantal overlijdens en het absolute aantal gevallen van euthanasie in België is voortdurend toegenomen sinds de invoering van de euthanasiewet. Deze toename suggereert dat men zich meer bewust is geworden van euthanasie als mogelijke optie aan het levenseinde en dat zowel artsen als patiënten in toenemende mate vertrouwd zijn met de

praktijk. Verschillende factoren kunnen een rol gespeeld hebben in deze ontwikkeling.

Ten eerste kunnen persoonlijke ervaringen met betrekking tot euthanasie de inwilliging van euthanasie hebben beïnvloed, gezien artsen zich mogelijk meer zelfzeker voelen vanwege de toegenomen ervaring met de praktijk. Ten tweede zijn er ook aanzienlijke inspanningen geleverd om artsen te informeren over euthanasie en de euthanasieprocedure, bijvoorbeeld via het LevensEinde InformatieForum (LEIF) dat artsen opleidt om aan andere artsen informatie te verstrekken over beslissingen rond het levenseinde. Ten derde worden er ook inspanningen gedaan om het bredere publiek te informeren over hun opties en rechten aan het levenseinde. LEIF biedt bijvoorbeeld niet alleen advies aan artsen over beslissingen rond het levenseinde, maar verstrekt ook informatie aan het bredere publiek over euthanasie en andere kwesties rond het levenseinde. Ten slotte is euthanasie in Vlaanderen vaak onderwerp van publiek debat. Populaire media kunnen dus een belangrijke rol gespeeld hebben in de toegenomen bewustwording van euthanasie als optie aan het levenseinde. Vooral spraakmakende gevallen van euthanasie bij personen die niet terminaal ziek zijn hebben het afgelopen decennium veel media-aandacht gegenereerd. Op deze manier kunnen zowel artsen als het bredere publiek zich steeds meer bewust zijn geworden dat niet alleen personen met aanhoudend en ondraaglijk lijden door terminale aandoeningen zoals kanker in aanmerking komen voor euthanasie.

De laatste jaren zagen we een verruiming van de euthanasiepraktijk in België, naar personen met een psychiatrische stoornis en ouderen, in het bijzonder mensen met dementie en multimorbiditeit. Terwijl euthanasie voor personen met een terminale aandoening algemeen aanvaard lijkt te zijn in België, is het debat opgeschoven naar euthanasie voor andere specifieke patiëntengroepen.

Naast België is euthanasie en/of hulp bij zelfdoding omwille van een **psychiatrische aandoening** ook mogelijk in Nederland, Luxemburg en Zwitserland. In andere landen zijn euthanasie en hulp bij zelfdoding beperkt tot personen met een terminale aandoening. Bezorgdheden betreffende euthanasie voor psychiatrische aandoeningen zijn doorgaans gerelateerd aan de wilsbekwaamheid van psychiatrische patiënten, de onomkeerbaarheid van de aandoening en de aard van het ondraaglijk lijden. De verschillende adviesteksten die het afgelopen jaar gelanceerd werden door een aantal organisaties, waaronder de Vlaamse Vereniging voor Psychiatrie, de Broeders van Liefde, het Raadgevend Comité voor Bio-ethiek en Zorgnet-Icuro, kunnen een belangrijke leidraad

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vormen voor artsen bij het beoordelen van euthanasieverzoeken van personen met een psychiatrische aandoening.

In België kunnen personen met **dementie** in een vroeg stadium in aanmerking komen voor euthanasie op basis van een actueel euthanasieverzoek. In de vroege stadia van dementie worden patiënten in staat geacht om hun situatie en prognose te begrijpen en hun wensen kenbaar te maken. Bij personen met gevorderde dementie is de besluitvormingscapaciteit bemoeilijkt waardoor euthanasie op basis van een actueel verzoek niet langer mogelijk is. Het is opmerkelijk dat de toename die we in euthanasie voor dementie aantreffen zich rond de tijd situeerde (meer bepaald in 2008) waarin schrijver Hugo Claus overleed door euthanasie omwille van de ziekte van Alzheimer. De euthanasie van Claus werd uitvoerig besproken in de media, wat mogelijk de aandacht op euthanasie heeft gevestigd als een mogelijkheid in geval van dementie.

De moeilijkheid bij euthanasieverzoeken in geval van dementie ligt niet alleen in het beoordelen van de vrijwilligheid van het verzoek en de aard van het lijden van de patiënt, maar ook in het kiezen van het juiste moment voor het uitvoeren van het verzoek, dat wil zeggen wanneer de persoon een periode heeft van wilsbekwaamheid en daardoor het euthanasieverzoek kan bevestigen. Verder leert de ervaring in Nederland, waar euthanasie voor gevorderde dementie op basis van een voorafgaande wilsverklaring wel mogelijk is, dat artsen in de praktijk niet geneigd zijn om euthanasie te verlenen in geval van gevorderde dementie

Specifieke aandacht is ook nodig voor de groep mensen die euthanasie kreeg vanwege **multimorbiditeit**, of polypathologie zoals dit genoemd wordt in de rapporten van de FCECE. Multimorbiditeit wordt gedefinieerd als de aanwezigheid van twee of meer chronische medische aandoeningen bij één persoon en is één van de meest voorkomende chronische aandoeningen bij volwassenen. Hoewel de aandoeningen afzonderlijk niet noodzakelijk fataal zijn, kunnen ze gecombineerd ondraaglijk en aanhoudend lijden veroorzaken dat niet kan worden verlicht. Multimorbiditeit wordt meer en meer erkend als een belangrijke uitdaging voor de volksgezondheid. Bijkomende aandachtspunten zijn dat multimorbiditeit vaker voorkomt in kansarme groepen en dat deze aandoening de kans op depressie significant verhoogt.

Euthanasieverzoeken omwille van levensmoeheid of ‘het voltooide leven’ zijn de laatste jaren in de voorhoede van het debat over euthanasie verschenen. Aangezien de aanwezigheid van een ernstige medische aandoening vereist is om in aanmerking te komen voor euthanasie vallen deze euthanasieverzoeken niet

binnen de euthanasiewet. De vraag kan gesteld worden of sommige van de over het algemeen oudere mensen met multimorbiditeit in zekere mate levensmoe zijn en vooral euthanasie willen omdat ze hun leven als voltooid ervaren. Dit benadrukt de complexiteit van het beoordelen van euthanasieverzoeken van deze patiëntenpopulatie en benadrukt de fijne lijn tussen wat mogelijk is binnen de grenzen van de wet en wat niet.

5.2. Een “grijze zone” tussen euthanasie en palliatieve sedatie

Euthanasie en palliatieve sedatie zijn beide een laatste redmiddel voor het verzachten van ondraaglijk lijden aan het einde van het leven. Terwijl euthanasie erop gericht is het leven van de patiënt te beëindigen door toediening van medicijnen in opzettelijk dodelijke dosis op uitdrukkelijk verzoek van de patiënt, heeft palliatieve sedatie als doel het bewustzijn van de terminaal zieke patiënt te verminderen of te verwijderen door sedativa toe te dienen.

Richtlijnen betreffende palliatieve sedatie stellen dat palliatieve sedatie enkel gericht is op het verzachten van refractair lijden en niet op bespoediging van de dood (als primair of secundair doel). Verder moet de beslissing worden genomen met de patiënt of, indien de patiënt niet competent is, met zijn of haar naasten.

Ons onderzoek wijst op het bestaan van een tussenliggende praktijk, of 'grijze zone' tussen euthanasie en palliatieve sedatie, waarin palliatieve sedatie wordt gebruikt met de intentie om het levenseinde te bespoedigen. Hoewel richtlijnen een duidelijk onderscheid maken tussen palliatieve sedatie en euthanasie, geven zorgverleners aan dat de grens tussen de twee praktijken soms vaag kan zijn. Dit is met name het geval wanneer er sprake is van een intentie (gedeeltelijk of expliciet) om het overlijden van de patiënt te bespoedigen, wanneer medicatie disproportioneel wordt verhoogd bij het uitvoeren van de sedatie, of wanneer de sedatie te vroeg wordt opgestart.

Uit eerder onderzoek in België en Nederland bleek dat palliatieve sedatie in de praktijk soms wordt besproken als een alternatief voor euthanasie. De redenen hiervoor kunnen te maken hebben met de medische situatie van de patiënt, bijvoorbeeld wanneer niet aan alle zorgvuldigheidsvereisten werd voldaan. Ook kunnen de persoonlijke redenen van de arts een rol spelen, aangezien artsen palliatieve sedatie als ethisch meer aanvaardbaar kunnen beschouwen omdat er geen duidelijke bespoediging van het overlijden is. Verder kan ook

instellingsbeleid tegenover euthanasie een invloed hebben op het al dan niet kiezen voor palliatieve sedatie.

Maatschappelijke controle over euthanasie kan mogelijk verbeterd worden door het introduceren van een extra controlesysteem voor monitoring van palliatieve sedatie. Het Universitair Ziekenhuis van Brussel startte in februari 2018 met dergelijke registratie. Registratie van palliatieve sedatie, met informatie over het besluitvormingsproces en uitvoering van palliatieve sedatie, kan een completer beeld geven van de euthanasiepraktijk, met name met betrekking tot de grijze zone tussen palliatieve sedatie en euthanasie. Registratie van palliatieve sedatie en het gebruik van gestandaardiseerde procedures kan mogelijk de zorgvuldige uitvoering van zowel palliatieve sedatie als euthanasie verbeteren.

5.3. Melding van euthanasie in vergelijking met euthanasie in grootschalige vragenlijststudies

In dit proefschrift werden twee vormen van melding van euthanasie, meer bepaald de wettelijk verplichte melding aan de FCECE en de niet wettelijk verplichte melding op het overlijdensattest, vergeleken met de euthanasiepraktijk zoals geschat door grootschalige representatieve vragenlijststudies gebaseerd op overlijdensattesten. Beide vormen van melding lijken een onderschatting te geven van de euthanasiepraktijk in vergelijking met de vragenlijststudie.

De belangrijkste reden voor het niet melden van euthanasie aan de FCECE lijkt verband te houden met de middelen die gebruikt worden om het levenseinde te bespoedigen en met de 'grijze zone' tussen euthanasie en palliatieve sedatie. Wanneer de door richtlijnen aanbevolen middelen voor euthanasie werden gebruikt, werd 92% van de euthanasiegevallen gemeld aan de FECEC. Wanneer niet-aanbevolen geneesmiddelen werden gebruikt, werd 4% gerapporteerd. Bovendien worden de meeste (93%) van de laatstgenoemde gevallen door de arts beschouwd als palliatieve sedatie of pijn- en symptoombestrijding. Sommige artsen overschatten mogelijk het levensverkortend effect van opioïden en sedativa. Anderzijds kunnen artsen die terughoudend zijn om euthanasie uit te voeren maar hun patiënt die euthanasie vraagt willen helpen, ervoor kiezen medicijnen te gebruiken die normaal niet met euthanasie worden geassocieerd om zo cognitieve dissonantie te verminderen. Een laatste hypothese is dat artsen zich niet aan de strikte procedures houden van de euthanasiewet omdat ze deze als te tijdrovend en belastend ervaren en de handeling daarom beschouwen als palliatieve sedatie.

Verdere opleiding van artsen over euthanasieprocedures en de effecten en bijwerkingen van opioïden en sedativa is nodig om te voorkomen dat euthanasie wordt uitgevoerd op een manier die nadelig kan zijn voor patiënten en hun naasten, en buiten maatschappelijke controle om gebeurt.

In slechts 16% van de gevallen die werden geïdentificeerd als euthanasie door middel van de vragenlijststudie bij artsen had de arts euthanasie als directe doodsoorzaak op het overlijdensattest aangegeven. Om een meer accurate registratie van euthanasie te bekomen is het aangewezen om het overlijdensattest aan te passen, bijvoorbeeld door een apart hokje te voorzien op het attest dat kan aangevinkt worden zoals in Nederland het geval is, en door artsen duidelijke richtlijnen te verschaffen over hoe euthanasie vermeld kan worden op het overlijdensattest.

5.4. Euthanasie en palliatieve zorg

In het internationale debat rond euthanasie wordt euthanasie vaak beschouwd als onverenigbaar met goede palliatieve zorg. De situatie in Vlaanderen zoals in dit proefschrift beschreven lijkt deze opvatting tegen te spreken. We vonden dat palliatieve zorg vaak betrokken is bij de zorg aan het levenseinde van mensen die euthanasie aanvragen en dat zorgverleners in de palliatieve zorg vaak betrokken zijn bij de euthanasieprocedure, ondanks de afwezigheid van een wettelijke verplichting om palliatieve zorgverleners te consulteren (de zogenaamde *palliatieve filter*). Deze bevindingen komen overeen met eerdere studies in België waarin werd vastgesteld dat euthanasie vaak voorkomt in het kader van multidisciplinaire zorg aan het levenseinde en dat Belgische artsen over het algemeen euthanasie beschouwen als deel van goede levenseindezorg.

Onze bevinding dat palliatieve zorg regelmatig betrokken is bij euthanasie is geen verrassende bevinding voor degenen die bekend zijn met de Belgische euthanasiepraktijk. De palliatieve zorgbeweging en het euthanasie-activisme ontwikkelden zich sinds het begin van de jaren tachtig geleidelijk naast elkaar, wat resulteerde in een gelijktijdige totstandkoming van wetten inzake euthanasie en palliatieve zorg in 2002. De Federatie Palliatieve Zorg Vlaanderen was verder de eerste professionele organisatie voor palliatieve zorg wereldwijd die euthanasie erkende als mogelijkheid aan het einde van een palliatief zorgtraject.

Meer bepaald vonden we dat palliatieve zorg bij 71% van de mensen die om euthanasie vroegen, betrokken was bij de zorg aan het levenseinde. Het zou niet wenselijk zijn dat alle mensen die euthanasie aanvragen en ontvangen,

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specialistische palliatieve zorg zouden ontvangen, omdat niet iedereen die euthanasie vraagt, noodzakelijkerwijs baat heeft bij de betrokkenheid van gespecialiseerde palliatieve zorgdiensten. Het valt echter aan te moedigen dat patiënten worden geïnformeerd over andere opties dan euthanasie en dat palliatieve zorg voldoende wordt geëxploreerd.

Rekening houdend met de geobserveerde stijging in euthanasie is het aangewezen dat de capaciteit van palliatieve zorg wordt vergroot. Gezien de uitgebreide ervaring van zorgverleners gespecialiseerd in palliatieve zorg met betrekking tot levenseindezorg, is het aan te moedigen dat zij betrokken zijn in de euthanasiepraktijk. Het zoeken van professionele ondersteuning bij euthanasieverzoeken, bijvoorbeeld door palliatieve zorg specialisten en LEIF-artsen en -verpleegkundigen, dient aanbeveling in geval van complexe casussen zoals bijvoorbeeld personen met multimorbiditeit, dementie of psychiatrische aandoeningen, of in geval van levensmoeheid.

Curruculum Vitae and list of publications of Sigrid Dierickx

Curriculum Vitae

Sigrid Dierickx (°1990) holds a master's degree in Sociology (2013, Ghent University) and Health Care Management and Policy (2014, KULeuven). In September 2014 she joined the End-of-Life Care Research Group (Vrije Universiteit Brussel & Ghent University) as a doctoral researcher to study the euthanasia practice in Belgium. Today she still works as a researcher at the End-of-Life Care Research Group and is involved in a study on supportive and palliative day care centres in Flanders.

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Rapportering van euthanasie in België: een trendanalyse, external seminar of the End-of-Life Care Research Group, 20 May 2016, Jette, Belgium (oral presentation)

Involvement of palliative care in euthanasia practice, 9th World Research Congress of the European Association for Palliative Care 2016, 9-11 June 2016, Dublin, Ireland (poster presentation)

Euthanasia for people with psychiatric disorders or dementia in Belgium: analysis of officially reported cases, 2nd International Conference on End of Life Law, Ethics, Policy and Practice, 13-15 September 2017, Halifax, Canada (oral presentation)

De betrokkenheid van palliatieve zorg in de euthanasiepraktijk: resultaten van een populatiestudie, Nederlands-Vlaamse Wetenschapsdagen Palliatieve Zorg, 30 November – 1 December 2017, Amsterdam, the Netherlands (poster presentation)

Appendix 1

Euthanasia registration form (2013)

REGISTRATION FORM EUTHANASIA

Form to be sent by registered mail with a proof of receipt to the Federal Control and Evaluation Committee for the application of the Act on Euthanasia, within four working days, to the following address:

***Federale Controle- en Evaluatiecommissie Euthanasie
Victor Hortaplein 40 bus 10 (verdieping 7C)
1060 Brussel***

References to articles of law in this document relate to the Act on Euthanasia of 28 May 2002 (Belgian Official Gazette of 22 June 2002).

TO AVOID CONFUSION

IN ACCORDANCE WITH THE LAW ON EUTHANASIA THE REGISTRATION FORM MAKES A DISTINCTION BETWEEN EUTHANASIA BASED ON A 'REQUEST FOR EUTHANASIA' AND EUTHANASIA BASED ON AN ADVANCE 'DIRECTIVE'.

THE REQUEST FOR EUTHANASIA CONCERNS THE REQUEST OF AN ILL PATIENT, WHO IS IN A MEDICALLY FUTILE CONDITION OF CONSTANT AND UNBEARABLE PHYSICAL OR MENTAL SUFFERING THAT CANNOT BE ALLEVIATED, RESULTING FROM A SERIOUS AND INCURABLE DISORDER CAUSED BY ILLNESS OR ACCIDENT (ART 3).

ON THE OTHER HAND, AN ADVANCE DIRECTIVE IS USED TO REQUEST EUTHANASIA BEFOREHAND, IN CASE ONE, AT A LATER TIME IN LIFE, WOULD END UP IN A STATE OF UNCONCIOUSNESS AND THIS CONDITION WOULD BE IRREVERSIBLE AND ONE WOULD SUFFER FROM A SERIOUS DISORDER CAUSED BY ILLNESS OR ACCIDENT (ART 4).

PART 1

Personal information relating to the patient, the physician, the consulted physicians and others.

This part is strictly confidential. It must be sealed by the physician and can only be opened by decision of the committee. Under no circumstance can it be used for the assessment task of the committee on behalf of the legislative Chambers.

1. the patient

1.1. surname:

1.2. first name:

1.3. place of residence:

2. the physician

2.1. surname:

2.2. first name:

2.3. registration number RIZIV¹:

2.4. place of residence:

2.5. e-mail

3. physician(s) whose consultation is required by law

3.1. second physician (in each case, art. 3§2,3° and art. 4§2,1°)

surname:

first name:

place of residence:

registration number RIZIV:

date of consultation:

3.2 in case the physician is of the opinion that the patient is not expected to die in the foreseeable future, a third consulted physician (art. 3§3,1°)

surname:

¹ RIZIV: Rijksinstituut voor ziekte- en invaliditeitsverzekering, National Institute for Health and Disability Insurance

first name:
place of residence:
registration number RIZIV:
date of consultation:

4. any others who were consulted (as stipulated in art. 3§2, 4°-6° and art. 4§2, 2°-4°)

4.1. surname:
first name:
capacity:
place of residence:
date of consultation:

4.2. surname:
first name:
capacity:
place of residence:
date of consultation:

4.3. surname:
first name:
capacity:
place of residence:
date of consultation:

4.4. surname:
first name:
capacity:
place of residence:
date of consultation:

4.5. surname:
first name:
capacity:
place of residence:
date of consultation:

4.6. **In case of euthanasia based on an advance euthanasia directive**

surname of the designated first proxy:

first name:

date of consultation:

surname of the designated second proxy:

first name:

date of consultation:

DATE, PHYSICIAN'S SIGNATURE AND STAMP

PART 2

Conditions and procedure under which euthanasia was performed.

This part of the document is strictly confidential; it will serve to allow the committee to verify whether the euthanasia was performed according to the conditions and procedures stipulated in the law.

It cannot contain any names (such as the name of the patient, the physician, institution, etc.).

1. the patient (do not mention name)

1.1. place and date of birth: .. / .. / ..

1.2. sex:

2. date of death: (d/m/y) .. / .. / ..

hour of death:

place of death (tick)

home

hospital

nursing home

other

3. precise diagnosis:

In case euthanasia was performed on a patient who was not conscious, based on an advance euthanasia directive, skip items 4 up until 12 and proceed to item 13.

4. nature and description of the constant and unbearable suffering:

5. reasons why this suffering could not be alleviated:

6. elements proving that the request was voluntary, well-considered and repeated, and did not originate from external pressure:

7. can it be assumed that the patient would have died in the foreseeable future?

yes

no

8. procedure followed by the physician (art. 3) (to be ticked and completed if followed)

existence of a euthanasia request in writing (art. 3§4)

date of the request: . . / . . / . .

compiled, dated and signed by the patient
or

compiled, dated and signed, in the presence of a physician, by an adult third party chosen by the patient without material interest

in the death of the person concerned

- mentioned the reasons why the patient was unable to put the request in writing and sign
- informed the patient of his/her health status and life expectancy (art. 3§2, 1°)
- discussed the request for euthanasia with the patient (art. 3§2, 1°)
- informed the patient about remaining therapeutic options and consequences (art. 3§2, 1°)
- informed the patient about palliative care and consequences (art. 3§2, 1°)
- established persistent physical or psychological suffering of the patient (art. 3§2, 2°)
- established that the request for euthanasia was repeated (art. 3§2, 2°)
- discussed the request for euthanasia with members of the nursing team (art. 3§2, 4°)
- discussed the request for euthanasia with relatives designated by the patient (art. 3§2, 5°)
- ensured that the patient discussed the request for euthanasia with the desired people (art. 3§2, 6°)
- recorded the course of the followed procedure and the written documents in the medical file (art. 3§5)

9. Independent physicians who were consulted as legally required (do not mention identity)

9.1 the second physician (art. 3§2, 3°)

physician's specialisation:

date of consultation: . . / . . / . .

recommendation of the consulted physician (according to his written report)

regarding **the serious and incurable character of the disorder and the constant and unbearable suffering that cannot be alleviated:**

9.2 if necessary, the third physician in case **the patient's death is not expected in the foreseeable future** (art. 3§3, 1°)

physician's specialisation:

date of consultation: . . / . . / . .

recommendation of the consulted physician (according to his written report) regarding **the constant and unbearable suffering that cannot be alleviated** and the **voluntary, well-considered and repeated character of the request**

10. other persons or authorities consulted (do not mention identity):

10.1 capacity:

date of consultation:

10.2 capacity:

date of consultation:

10.3 capacity:

date of consultation:

10.4 capacity:

date of consultation:

10.5 capacity:

date of consultation:

11. the manner and drugs used in performing euthanasia:

12. additional information the physician wishes to impart:

The following items 13 up until 19 concern euthanasia cases involving a patient who WAS NOT CONSCIOUS, based on an advance euthanasia directive.

13. existence of a properly formatted advance directive according to the model determined by Royal Decree of April, 2 2003

date of the document: . . / . . / . .

compiled, dated and signed by the patient

compiled, dated and signed, in case the patient was physically unable, by an adult third party chosen by the patient without material interest in the death of the person concerned

the reasons why the patient was unable to put the request in writing and sign are mentioned

a medical certificate is enclosed vouching for the impossibility (of the patient to sign)

one or more proxies were designated

the course of the followed procedure and the written documents are recorded in the medical file (art. 4§2, 4°)

14. the unconscious state of the patient was irreversible

15. independent physician consulted (art. 4§2, 1°):

physician's specialisation:

date of consultation: . . / . . / . .

physician's recommendation concerning the patient's irreversible medical condition:

16. discussion with the proxies designated in the advance directive (art. 4§2, 3°)

discussion with the nursing team (art. 4§2, 2°)

discussion with the patient's relatives, designated by the proxies (art. 4§2, 4°)

17. any other persons or instances consulted (**do not mention name**)

17.1 capacity:

date of consultation

17.2 capacity:

date of consultation

17.3 capacity:

date of consultation

17.4 capacity:

date of consultation

18. the manner and drugs used in performing euthanasia:

19. additional information the physician wishes to impart:

Appendix 2

Extract of the model of the death certificate in Belgium

STROOK C

OVERLIJDEN VAN EEN PERSOON VAN EEN JAAR OF OUDER

(Strook in te vullen en onder gesloten omslag te plaatsen door de *geneesheer*)

1. Aard van het overlijden

- natuurlijke oorzaak
- verkeersongeval
- ander ongeval
- zelfmoord
- doding
- wordt onderzocht
- kan niet bepaald worden

2. Indien de doodsoorzaak niet natuurlijk is, beschrijf de omstandigheden

.....

.....

.....

.....

Voorbehouden

--	--	--	--

3. Ongeval

3.1 Plaats van het ongeval

- openbare weg
- thuis
- andere, preciseer
- werkplaats (of school voor kinderen)
- onbekend

3.2 Datum en uur van het ongeval

- datum (DDMMJJJJ)

--	--

 /

--	--

 /

--	--	--	--
- uur (UUMM)

--	--

 u

--	--

 m

4. Doodsoorzaak (1)		Duur (2)
----------------------------	--	-----------------

I. Ziekte of aandoening die rechtstreeks de dood tot gevolg had

Logische samenhang van de ziekten/aandoeningen die geleid hebben tot de onmiddellijke doodsoorzaak onder a). Bij vermelding van meerdere ziekten de aan het overlijden ten grondslag liggende het laatst opgeven ("oorspronkelijke doodsoorzaak")	a) ..	Euthanasia	
		veroorzaakt door :	
	b) ..	Cancer	
		veroorzaakt door :	
	c) ..		
		veroorzaakt door :	
	d) ..		
	e) ..		
	f) ..		
	g) ..		

(1) Hier wordt niet de wijze van overlijden bedoeld zoals bvb. : hartfalen, syncope, enz... maar de ziekte, het trauma of de complicatie die de dood veroorzaakte. Gelieve slechts één oorzaak per lijn te vermelden.

(2) Tijdsinterval (bij benadering) tussen het begin van de ziekte/aandoening en de dood (preciseer zo nodig in minuten, uren, weken of maanden, ...)

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