The euthanasia practice in Belgium

Evaluation of the mandatory consultation procedure between physicians

Yanna Van Wesemael

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Yanna Van Wesemael

Doctoral dissertation

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Chapter 2: Van Wesemael Y, Cohen J, Bilsen J, Smets T, Onwuteaka-Philipsen B, Deliens L. Process and outcomes of euthanasia requests in Belgium under the euthanasia act: a nationwide survey. Journal of Pain and Symptom Management 2011, in press.

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Part I

Introduction

To be, or not to be: that is the question:
Whether 'tis nobler in the mind to suffer
The slings and arrows of outrageous fortune,
Or to take arms against a sea of troubles,
And by opposing end them? To die: to sleep;
No more; and by a sleep to say we end
The heart-ache and the thousand natural shocks
That flesh is heir to, 'tis a consummation
Devoutly to be wish'd. To die, to sleep;

Shakespeare - Hamlet

Chapter 1

Introduction to this dissertation

Introduction

In this dissertation we will describe the process and outcomes of euthanasia requests and evaluate the particular practice of consultation between physicians, within the context of the Belgian euthanasia law.
At the end of life, euthanasia is only one of the decisions that can be made and it is a practice that occurs rarely in Belgium. In 2007, only 1.9% of deaths in Flanders were the result of euthanasia (1), i.e. life-ending at the patient's explicit request, which has to be performed by a physician. This definition corresponds to the legal Belgian definition and finds its origin in the Netherlands, where a specialist in health law formulated it first in 1977 (2)(3). Distinctions have been made - and are still being made in some countries - between active and passive, voluntary and involuntary euthanasia by many authors but the above-mentioned definition is the one used for research in Belgium and hence also for this dissertation. Official organizations like the European Association for Palliative Care (EAPC) have also advocated to use this definition (4)(5).

Before going into detail in the research questions of this dissertation, we will sketch a general historical background of the meaning of euthanasia, the background of the Belgian euthanasia law and an overview of euthanasia laws in other countries. We will also give an overview of the past research regarding this subject in Belgium and shortly describe the Life End Information Forum (LEIF), a Flemish organization providing in trained consultants in euthanasia requests.

Historical background on euthanasia

The term euthanasia has a long history and its concept has had different meanings over the centuries. It was first used in ancient Greece, literally meaning a good death (happy, painless, gentle, noble and in moral perfection) (6). Despite the Hippocratic Oath of 400 B.C., which prohibited physicians from giving a lethal drug to a patient, not even if asked for it, assisted dying was common for all kinds of diseases (7)(8). It became more a subject of taboo during the Middle Ages because it was condemned in Judeo-Christian tradition (9) (10). During the Age of Enlightenment, several philosophers and scientists challenged the institution of Church, including its ethical views. This eventually led to the church having less impact on society and a shift of values towards an emphasis on autonomy. In the light of intellectual debate, euthanasia became a subject of discussion among philosophers like Locke and Hume (11).

In the Anglo-Saxon world, the debate on euthanasia became more concrete when in 1870 active euthanasia with chloroform by medical practitioners was openly advocated in a book titled 'Euthanasia' (12)(13)(14). The meaning of euthanasia became the accelerated death of a dying person with the help of medicine in order to avoid suffering (15). However, in Germany the term gained very negative connotations in the years surrounding World War II, during which the Nazis killed physically and mentally disabled people by the so-called *Aktion T4* euthanasia program (16)(17). These tragic events reinforced the fears of a 'slippery slope', i.e. the fear that vulnerable persons like the handicapped or the elderly would euthanasia more easily or against their will.

The current euthanasia discussion and the legal changes occurring in several countries have emerged due to various developments. There have been changes in the medical area, for example progress in medical technology, like the development of antibiotics, anaesthetics and surgical techniques in the 19th century, which brought with it the possibility to postpone death. It eventually led to the medicalization of the end of life: patients more often died in hospitals, surrounded by the latest technologies to keep them alive instead of at home surrounded by family.
Especially with cancer becoming the main cause of death in Western countries in the 20th century, alleviating pain became more important (18)(19). This led to the discussion on a

hastened death as a double effect of alleviating pain and to confusion of the practice of alleviating pain with euthanasia (20).
There were also societal changes that led to the current debate on euthanasia; a higher value was placed on personal autonomy which in the medical field meant that the patient's position grew stronger (21). The role of the patient changed from that of a passive receiver of care, dependent on the doctor, to an active participant in decision-making. Being able to control the time and manner of one's own death is also considered by some as an aspect of a good death (22). In the last 40 years, euthanasia has become subject of debate among ethicists, physicians and politicians and scientific research about the subject has expanded widely (23)(24)(25)(26)(27)(28).

Dying in contemporary society: the importance of medical end-of-life decisions

Today, euthanasia, physician-assisted suicide and life-ending without explicit request by the patient are practices that occur in Western society, regardless of existing legal regulation (29-33). But there are also other medical end-of-life decisions that can be made by the patient, the treating physician and/or the family of the patient. When a patient enters the terminal phase of an illness, when treatment is not effective or is even unnecessarily prolonging life, one can, for example, decide to stop treatment where it has become futile or if the physical costs (e.g. more fatigue, too heavy side-effects of treatment) outweigh the benefits. Or, in cases of pain, one can ask to increase pain medication. Such decisions influence the dying process and in some cases also the time of death. In Flanders, in 2007, these medical end-of-life decisions were made in 48% of deaths (1). An overview of the different medical end-of-life decisions is given in Box 1 (34)(35).

Box 1: overview of medical end-of-life decisions and their definition and occurrence in Flanders in 2007 (1)

Type of medical decision	%
1. Non-treatment decision: the withholding or withdrawing of treatment, taking into account the possibility or the certainty that this will hasten the patient's death.	17.4
2. Intensification of the alleviation of pain and symptoms by using drugs (e.g. morphine), taking into account a possible life-shortening effect.	26.7
3. Continuous deep sedation until death: the administration of drugs to keep the patient continuously in deep sleep until death, often accompanied with forgoing the administration of nutrition and hydration.	14.5
4. Euthanasia: the administration of lethal drugs by a physician to end a patient's life at their own explicit request.	1.9
5. Physician-assisted suicide: the prescription or supply of lethal drugs with the intention of helping the patient end their life.	0.07
6. Life-ending drug use without the patient's explicit request.	1.8

Some of these decisions (number 4, 5 and 6) indisputably have a life-shortening effect, while for the others, research and debate concerning the life-shortening effect is inconclusive. Regarding the use of morphine and the practice of continuous deep sedation, opinions are divided among researchers and clinicians, although they are generally accepted as normal medical practice, unlike euthanasia or assisted suicide (36-41).

Legalized euthanasia and assisted suicide in the world

In Belgium

Since this dissertation covers the subject of euthanasia practice in Belgium, we will start with describing how the law came into effect in this country, after which we will describe chronologically similar policies and laws in other countries.

History of the euthanasia law

Belgium is one of three countries currently having legalized euthanasia, the others being the Netherlands and Luxembourg. The initial development of the euthanasia law started with the founding of two Right to Die Associations in Flanders and Wallonia in 1980 which with limited influence at that time, tried to advocate the right to euthanasia (42). In the following period, the process leading to the formation of the law was mainly a political one with laws proposed by individual Liberal and Social-Democrat members of Parliament. In the next 20 years, several other law proposals followed but none was accepted mainly because the political party reigning during that whole period, the Christian Democrats, were opposed to the legalization of euthanasia. Yet, the failed attempts to come to establish a euthanasia law led in 1997 to the Advisory Committee for Bioethics formulating an advice concerning euthanasia, palliative care, treatment disposition and living wills. The 35 members of this Committee – physicians, lawyers, ethicists, psychologists and sociologists - represented the different languages and ideological views of Belgium. Due to this diversity in ideological convictions, the committee came up with not one advice, but four different proposals representing the different opinions of its members (43):

1. An amendment of the penal code, making euthanasia no longer punishable. There would be certain conditions for performing euthanasia: a physician has to perform it and there must be a control procedure *a posteriori*.
2. Euthanasia is kept in the penal code, but under certain conditions the physician who performs euthanasia is considered as acting in a situation of emergency. These conditions are the following: the patient must be suffering unbearably, their request must be well-considered and repeated, the performing physician must consult with a colleague beforehand, he/she must inform the family and the caring team about the euthanasia and must use the appropriate medicine to perform euthanasia. The decision to perform euthanasia lies only with the patient and the physician. For the societal control *a posteriori*, the physician must fill out a registration form and report the case of euthanasia to the judicial authorities.
3. Installing formal procedures for all kinds of medical end-of-life decisions. Regarding euthanasia, more emphasis is put on consultation with the caring team and the family as well as a third person who is not a physician and who is appointed by a local ethical committee. Societal control afterwards is also necessary.
4. The fourth proposal pleads for a preservation of the legal prohibition of euthanasia, in other words keeping the situation as it is. Legal and medical institutes must give priority to the preservation of life. Other means can be employed to relieve suffering.

The proposals of the committee were the starting point for a serious debate between the members of Parliament and experts who came to the Senate to give their opinions. After two days of intensive debate, most political parties found it possible to side with the third proposal. The Flemish liberals and both French and Flemish social-democrat parties preferred the second proposal. It wasn't until the next elections in 1999, which removed the Christian Democrats from power, that the euthanasia bill came back on the political agenda. In the meantime, a debate in civil society voiced by the media and among healthcare professional organizations, virtually absent until then, had also grown stronger. Also in that year, the Advisory Committee on Bioethics formulated an advice concerning the termination of life of incompetent patients but this advice was not so influential as the previous one on euthanasia with competent

patients. In the next few years, bills on euthanasia were submitted and re-submitted and a euthanasia debate was started in the Joint Commissions of Justice and Social Affairs. At the end of 1999, six senators came up with three joint bills, one of them concerning palliative care, but it took some time, additional discussions in the Joint Commissions of Justice and Social Affairs and amendments before there was a vote on it. In March 2001, the amended euthanasia bill was passed by the Joint Commissions of Justice and Social Affairs , after which it went to the Senate and the House of Representatives (44). The bill was approved by the Senate in October 2001 and in May 2002 by the Chamber of Representatives. The law came into effect in September 2002.

The euthanasia law

In the final euthanasia law of May 28th 2002 (45)(3), euthanasia was defined as intentionally ending another person's life at that person's request. Euthanasia has to be performed by a physician. Several due care requirements were installed. First of all, the patient must be of age or an emancipated minor (no more under the responsibility of the parents) and mentally competent at the moment the request is made. The request must be voluntary, well-considered and repeated and not formulated under external pressure. The patient must be in a medically hopeless situation of unbearable physical or psychological suffering that cannot be alleviated and that is caused by a serious and incurable condition, due to illness or accident. The attending physician has to inform the patient about their health condition and the therapeutic possibilities. He/she also has to be convinced of the unbearable suffering through several conversations with the patient. The request should also be discussed with the caring team and, if the patient wishes, with the next of kin.

Also, control mechanisms before and after euthanasia is performed were incorporated. Before proceeding with euthanasia, the attending physician must consult a second physician who is independent from both the attending physician and the patient. The purpose of this is that the second physician can check the due care requirements and provide an objective opinion of the request. According to the law, this second physician must read the medical file, examine the patient and ascertain that the patient's suffering is unbearable and cannot be alleviated and write a report about his findings. The (non-binding) advice of this second physician must be added to the medical record and to the notification form if euthanasia is performed (46). If the physician judges that the patient will not die in the near future, a third independent physician who is a specialist in the disease or a psychiatrist must be consulted. This physician has to perform the same tasks as the second physician. For non-terminal patients, there has to be a one-month time lapse between the request and euthanasia.
The law does not clarify the independence between the consulting physicians and between the consultant and the patient. It has been operationalized in juridical literature as follows: the consultant should not be a family member of the patient or a co-attending physician. Furthermore there should be no hierarchical nor family ties between the two physicians. If the attending physician works in a hospital, the consultant does not necessarily have to come from outside the hospital (47). Other authors warn for ambiguous relationships between physicians working in the same hospital (48). In a Dutch protocol regarding consultation it is stated that the consultant should "not have any business, hierarchic or family connections with the consulting physician or the patient" and that the consultant should give particular consideration to the independence if he works in the same (smaller) institution as the attending physician (49). In our studies, we will use the operationlization of independence as stated in the Dutch protocol.

A second control mechanism takes place after euthanasia has been performed. The attending physician must then report the euthanasia to the Federal Control and Evaluation Committee on Euthanasia within four working days by means of a registration form consisting of two parts. One part is sealed by the physician and contains the names of the patient, the attending

physician and the physicians and other persons who have been consulted. The second part contains anonymous information about the patient as well as information about the the nature of the medical condition, the request, the suffering, the followed procedures, the background of the consultant and the medication used for euthanasia. The Committee will evaluate the euthanasia case based on this second part (50). If a majority of the members of the Committee suspects that the due care requirements were not met, they will open the sealed part of the registration and possibly contact the physician for the medical file of the patient or more information. If they decide that the due care requirements were not met, they refer the case to the Public Prosecutor. Up until now, no case has been referred (51).

A physician is not obliged to perform euthanasia even if the due care requirements are met. He can decide on personal or moral grounds to not grant the request. The law does not comprise an obligation to refer the patient to another physician who is willing to perform euthanasia. The initiative to find another physician lies with the patient. However, some authors argue that physicians should take the responsibility to refer the patient to a colleague in cases where they do not want to perform euthanasia because physicians have a duty to continue care, which entails that they cannot interrupt a treatment without taking follow-up measures (52)(53).

The law also does not include regulation of physician-assisted-suicide, though suicide itself is not illegal in Belgium. The Federal Control and Evaluation Committee on Euthanasia does, however, permit this practice as it is deontologically comparable to euthanasia. All due care requirements for euthanasia must be met and the treating physician must be present when the patient takes the life-ending medication. The Belgian Order of Physicians also adheres to this view (54).

Furthermore, the law provides the possibility for a patient to formulate an advance directive concerning euthanasia. This directive applies in case where the patient suffers from a serious and incurable condition and is in an irreversible condition of unconsciousness. The directive must be drawn up in the presence of two witnesses, one of which must not have a material interest in the patient's death. The advance directive holds for five years, after which it has to be renewed.

Laws on palliative care and patient rights

Together with the enactment of the euthanasia law came the ratification of the law on palliative care which aims to guarantee the access to palliative care for every patient and determines measures for the further development of palliative care services (55). For many politicians, it was crucial to make adequate palliative care possible for everyone when euthanasia became a legal option.

Another law, adopted almost simultaneously with the euthanasia law, was the law on patient rights establishing the rights of patients to be informed and to consent to treatment decisions. This law enhances even more the active role that patients now play in their treatment (56). Patients are now free to choose their physician, but they can also choose what treatment to have or not have. Furthermore, the law stresses the possibility of patients formulating a living will in which they state which treatments they do not want in the case of becoming mentally incompetent. They can also officially indicate a representative to advocate their rights.

Implications of the euthanasia law on palliative care

A year after the law became effective, the Federation for Palliative care, the coordinating body of palliative care in Flanders and a centre for knowledge and expertise on palliative care, has formulated its concept of euthanasia within palliative care. The organization stated that palliative care and euthanasia are neither alternatives nor opposites (57). The Federation recognizes that even with the best palliative care, unbearable physical or psychological

suffering can persist and drive a patient to choose euthanasia. A request for euthanasia should always be a reason for the physician to evaluate and, if necessary, adjust his or her care practices. Also, the Federation stresses the importance of discussing the request amongst caregivers. The Federation pleads for a preceding palliative consultation to be incorporated in the euthanasia law. Furthermore, the Federation suggests that the physicians within the palliative care teams can act as second independent physicians in the euthanasia procedure, as long as they do not take over the role of the attending physician and perform euthanasia themselves. Recently, the Federation has formally reaffirmed that palliative teams are open to requests for euthanasia and that they have the necessary expertise to handle them carefully (58).

The view of the Belgian Federation contrasts with that of the European Association for Palliative Care (EAPC) that formulated an advice clarifying their position towards euthanasia (5). They encourage debate around euthanasia and physician-assisted suicide but in their opinion these practices should not be part of the responsibility of palliative care. The Association is concerned that legalization of euthanasia may lead to a slippery slope, pressuring vulnerable people like the elderly and disabled people to choose for euthanasia. Furthermore, there is concern that it would lead to the underdevelopment and devaluation of palliative care.

Euthanasia and physician-assisted suicide in the rest of the world

Belgium may be one of the few countries to legalize euthanasia but it has certainly not been the pioneer in the matter.

The Netherlands

The first country in the world to have a meaningful policy on euthanasia is without any doubt the Netherlands (21; 59; 60). It was also a Dutch specialist in health law who in 1977 formulated a definition of euthanasia that would become the definition used in the Dutch, Belgian and Luxembourg law (2).
Although the Dutch voted a law on euthanasia the same year as the Belgians, they had quite a long history of tolerance and practice regarding euthanasia. The starting point was in the 1960s, when societal changes occurred on taboo subjects (legalization of abortion, sexual revolution, etc.). As regards euthanasia, things changed substantially in the beginning of the seventies, when a physician stood trial for killing his mother at her own request. As a result of this trial, the District Court formulated a set of conditions for the shortening of life under a policy of tolerance: the patient had to be incurably ill, had to suffer unbearably, mentally or physically, had to express the wish to die and the doctor should be the one acceding to the request (61). In the following years, other requirements were added, among them the consultation of a second physician. Pressure groups like the Dutch Association for Voluntary Euthanasia (NVVE) and the Royal Dutch Medical Association were responsible for these changes. Another court case in 1981 led to the tolerance of assisted suicide, provided that due care requirements were met. The National Committee of Procurators-General decided that all cases of assisted death on request should be notified to a special committee. In 1984, the Medical Association published a new policy on euthanasia that fine-tuned the substantive (referring to the patient and their request) and procedural due care requirements (62). In that same year, a first bill was submitted in Parliament with the intention of regulating legally what was already happening in practice. However, the government argued that the time was not yet right for such a law and the following government proposed that a study on the practice of euthanasia should be conducted before voting in a law. Two such studies took place in 1990 and 1995, showing the incidence and characteristics of euthanasia and the degree to which physicians complied with the due care requirements (34)(63). The Law on Termination of Life on Request and Assisting Suicide, which contained all the due care requirements built up over 30 years of practice, finally came into effect in 2002 (59).

Australia

The first country to pass a law on euthanasia was actually Australia, where the regional Northern Territory Parliament passed the Rights of the Terminally Ill Act in 1995 (64). The law came into effect in 1996 and regulated medically-assisted suicide for terminally ill patients. One of the requirements was that the request should be supported by three physicians including a specialist and a psychiatrist. However, in 1997 the Act was repealed due to opposition in the National Parliament. Only seven people had made use of the law to die with medical assistance (65).

The United States

In the state of Oregon in the USA, physician-assisted suicide has been legalized as of 1997 (66). The law allows terminally ill patients to receive prescriptions for self-administered lethal medications from their physicians. Euthanasia is not permitted. The patient must reside in Oregon, be of age, mentally capable and have an illness that is expected to lead to death within six months. The patient must make one written and two oral requests, separated by 15 days, to their physician. Both the attending physician and a consultant have to confirm the diagnosis of a terminal condition and assess the mental competence of the patient. After prescribing the medication, the attending physician must report this to the Oregon Health Division.
In 2009, the same law was passed in the state of Washington (67).
In December 2009, the Montana Supreme Court ruled that state law protects physicians from being prosecuted when they perform assisted suicide (68).

Luxembourg

Luxembourg's euthanasia law came into effect in 2009, but it brought an important constitutional change with it (69). The Great Duke, monarch of Luxembourg, threatened not to sign the bill for personal philosophical reasons. The constitution of the country was modified, resulting in a reduction of power for the Great Duke, after which the law could be enacted (70). This law is very similar to the Belgian law and imposes the same substantive and procedural due care requirements. It does however also regulate physician-assisted suicide. Together with this law, another law on palliative care and advance directives also came into effect (71).

Mandatory consultation of a second physician and the Life End Information Forum (LEIF)

After the euthanasia law was adopted in Belgium, there was still a lot of uncertainty among physicians on how to handle euthanasia requests from their patients, mainly because it would not be easy to find a second (and sometimes a third) physician to consult with in these cases. For that reason, some individual professionals in palliative care and the association Right To Die with Dignity founded the Life End Information Forum (LEIF), in 2003 in Flanders and Brussels (72). It was based on the example of an organization in the Netherlands, called SCEN (Support and Consultation in Euthanasia in the Netherlands). SCEN was established in 1997, when euthanasia was not legal yet but tolerated, and provided specially trained general practitioners (GPs) – SCEN physicians - who could be consulted as the mandatory second physician in euthanasia requests for other general practitioners (and as of 2007 also for specialists; before that date, specialists only consulted with non-SCEN physicians) (73). The objectives of the Belgian LEIF, however, reached further than those of SCEN. The founders of LEIF thought that there was just as much uncertainty among physicians about other medical end-of-life decisions as there was about euthanasia. This is why the LEIF-physicians are also trained to provide consultation in other end-of-life decisions to their colleagues and to inform physicians as well as patients and the wider public, on matters of end-of-life care. The organization of LEIF and a comparison with SCEN is discussed in detail in chapter 4.

Research on euthanasia in Belgium

There has already been extensive research on the subject of euthanasia in Belgium, even before it was legal. For instance, public acceptance of euthanasia, measured through the European Values Study, was found to be rather high in Belgium and had increased substantially between 1981 and 2000 (74) (75).

Since 1998, several studies based on death certificates have monitored the incidence of different medical end-of-life decisions in Flanders, including euthanasia (1; 76-78). Trends analyses showed an increase in the practice of euthanasia (from 1.1% to 2.0%) and a decrease in life-ending drug use without patient request (from 3.2% to 1.8%) between 1998 and 2007 (79). The authors concluded that the euthanasia law had an impact on all end-of-life decisions and, based on detailed analyses of the due care criteria and shifts within specific patient groups, that it did not lead to a slippery slope but, rather, to the contrary (80).

Concerning the characteristics of patients receiving euthanasia, the death certificate study of 2007, based on a representative sample of 6927 deaths, has demonstrated that euthanasia occurs predominantly in patients younger than 80 years, with cancer and dying at home (81). A study on reported euthanasia cases also examined the characteristics of patients who received euthanasia. The majority of these patients had cancer (83%) and the registering physician reported physical (96%) and psychological (68%) suffering (82).

Another study has focused on the notification of euthanasia to the Federal Control and Evaluation Committee. Based on the aforementioned death certificate study of 2007, it found that approximately half of euthanasia cases (53%) were reported to the Committee. The most recurring reason for not reporting was the fact that the physicians did not perceive their act as euthanasia. Furthermore, the treating physician less often consulted with another physician in unreported cases than in reported cases (55% vs 98%) (83). Also regarding the notification of euthanasia, the majority of cases between 2002 and 2007 were reported in Dutch, while only 17% came from French-speaking physicians (82). There is little evidence on whether this difference might be due to differences in medical end-of-life practices. A mortality follow-back study of 2005-2006 via the Sentinel Network of General Practitioners found that end-of-life

decisions in general were more prevalent in the Dutch-speaking community than in the French-speaking community but the prevalence of euthanasia was not statistically different between the two communities (84). Hence, it is not know whether physicians in the French-speaking community receive fewer requests for euthanasia, perform it less often and/or report their practice less often.

Regarding the mandatory consultation between physicians in euthanasia requests, very little research has been conducted in Belgium. In the above-mentioned death certificate study in Flanders of 1998, discussion with a colleague was found to have taken place in 48% of euthanasia and physician-assisted suicide cases but this was not the mandatory consultation as intended by the euthanasia law since there was no law at that time (77). In the following studies of 2001 and 2007, a question on discussion with another physician in case of a euthanasia request was sought but here too, it did not refer to the mandatory consultation. Discussion with a colleague took place in 78% of euthanasia cases in 2007 (81).
The study on the reported cases of euthanasia showed that a second physician was consulted in 99.8% of cases (in 0.2% of cases, the information on consultation and on contact with physicians by the Committee, was missing). Attending physicians consulted with additional physicians, other than the mandatory second physician, in one third of cases (82).
So far, no large scale studies in Belgium or Flanders have described the consultation process, the quality of consultation or the views of Belgian physicians concerning this control mechanism in the euthanasia law.

Research aims

This dissertation aims to provide insight into the way physicians handle euthanasia requests and the consultation with a second independent physician in these cases.

The following research questions will be addressed:

Regarding euthanasia requests and the manner in which they are handled by physicians:

1. *How do physicians in Belgium receive and handle euthanasia requests by their patients?*
    - Which physicians, likely to be involved in end-of-life care, have received a euthanasia request from a patient since the implementation of the euthanasia law?
    - What are the main reasons for requesting euthanasia?
    - What are the outcomes of euthanasia requests in Belgium?
    - How often does an attending physician consult a second physician in a euthanasia request in Belgium?
    - What patient, physician, process and request characteristics are associated with a request for euthanasia being granted?

2. *What are differences between Flanders and Wallonia in terms of attitudes towards euthanasia and the euthanasia law and in terms of how requests are handled?*

Regarding the consultation service LEIF:

3. *How is the specialized service providing consultants in euthanasia requests in Flanders (LEIF) organized and how does it compare to the similar service in the Netherlands (SCEN) in terms of development, aims, tasks and functioning?*

4. *What are the characteristics of LEIF physicians and what is their role and involvement in euthanasia requests in Flanders?*

- What training and experience in end-of-life care do LEIF physicians have?
- What are the types and the frequency of requests that LEIF physicians are confronted with?
- What is the actual involvement of LEIF physicians in euthanasia cases?

5. *To what extent is LEIF successfully implemented in Flanders and Brussels?*
   - How many physicians know of the existence of LEIF?
   - How many physicians have made use of LEIF in the past as part of a euthanasia request?
   - To what extent do physicians feel supported by the idea that they can contact a LEIF physician for consultation in case of euthanasia requests?
   - How many physicians would consider using LEIF in the future ?

Regarding the mandatory consultation in euthanasia:

6. *What are the characteristics and the quality of consultations with a second physician in euthanasia requests?*
   - To what extent are the legal requirements of the euthanasia law met during a consultation with a second physician?
   - To what extent does a consultation with a LEIF physician differ from a consultation with a non-LEIF physician in terms of legal requirements and other quality criteria?

7. *How does a consultation with a LEIF physician compare to a consultation with a SCEN physician in terms of quality criteria?*

Methods

This dissertation is based on four different studies: a nationwide physician study, a survey of all LEIF physicians and attending physicians cooperating with a LEIF physician, the SCEN registration and the European Values Study.

Nationwide physician study

A self-administered questionnaire was sent in 2009 to 3006 Belgian physicians likely to be involved in the care of dying patients, namely general practitioners, anaesthesiologists, gynaecologists, internists, neurologists, pulmonologists, gastroenterologists, neuropsychiatrists, psychiatrists, cardiologists, radiotherapists, and surgeons. The sample was stratified for province and speciality and represented a sampling fraction of 9.2%. For each province, a random proportional sample was drawn for each speciality. The questionnaire was based on questionnaires previously used in six European countries and Australia (85). It was developed in Dutch and translated forward and backward into French for use in the French-speaking part of Belgium. It was tested with 10 expert physicians in palliative care. The eight-page questionnaire was sent to all physicians in the sample with follow-up mailing according to the Total Design Method (86). The completed questionnaires were to be sent back to a lawyer who acted as intermediary to guarantee anonymity.
Aside from socio-demographic information, physicians were asked about their experience with euthanasia requests, their attitudes concerning consultation in euthanasia requests and concerning LEIF and were also asked to describe the last euthanasia request they received from one of their patients. The response to the questionnaire was 34% (n=914). More details on this methodology are provided in chapters 2, 3, 5 and 7. An example of the questionnaire can be found in the appendix.

Study with LEIF physicians and attending physicians

The study consisted of two parts:

1. All *LEIF physicians* having followed at least two modules of the LEIF training were sent a survey through the LEIF secretariat questioning their activities during a one-year period (number of consultations in euthanasia requests or other medical end-of-life decisions, number of times they gave information or advise) and their last consultation as a mandatory second or third physician in a euthanasia request in the past year.
2. If the LEIF physician had described his last consultation, he or she was asked to send another questionnaire to the *attending physician* who had requested the consultation.

Both physicians were asked to send the completed questionnaire to the researchers. The response rate for the LEIF physicians was 75% (n=96) and for the attending physicians who consulted with a LEIF physician 58% (n=40).
This 2008 study was based on an evaluation study that was performed in the Netherlands with SCEN physicians. It was carried out five years after LEIF was founded. Where possible, the same questions were used to allow for comparisons between both countries. More information on this methodology is provided in chapter 6 and 8. An example of each questionnaire can be found in the appendix.

The SCEN registration

In the Netherlands, SCEN physicians have to fill out a registration form after they have done a consultation. Between April 2000 and December 2002, the EMGO Institute for Health and Care Research of Amsterdam collected these registrations and requested these SCEN physicians to send a questionnaire to the general practitioner who requested the consultation. At that time, SCEN had been active for five years, making the data comparable to the Belgian data regarding period of activity. The GPs returned the questionnaire anonymously to the researchers after which they were linked to the registration forms of the SCEN physicians by a corresponding serial number (87). Only the last registration form from each SCEN physician was retained as the Belgian study also only evaluated the last consultation. Response percentage for both the SCEN physicians and the attending physicians was 100%.
Access to the database was negotiated with the EMGO. More information on this methodology is provided in chapter 8.

The three aforementioned studies guaranteed the anonymity of the participating physicians by means of recoding or the use of an intermediary. All studies were also approved by the local Ethical Committees.

European Values Survey

We used the Belgian data of the European Values Survey, which took place in 2008 in 47 European countries. In each country, a representative multi-stage or stratified random sample of the adult population of the country 18 years and older was approached for face-to-face interviewing. One question from the questionnaire asked about the respondent's acceptance of euthanasia. A total of 791 people from Flanders and 591 from Wallonia were surveyed (response 69%). More information on this methodology is provided in chapter 3.

Outline of the dissertation

This dissertation consists of four main parts. Part 2 addresses euthanasia requests received by Belgian physicians who are likely to be involved in the care of dying patients. Chapter 2 is about the process and outcomes of these euthanasia requests and chapter 3 describes the differences in euthanasia practice and attitudes between Dutch-speaking Flanders and French-speaking Wallonia.

Part 3 goes deeper into the organization of the Life End Information Forum (chapter 4), the implementation of LEIF (chapter 5) and the role and involvement of LEIF physicians in euthanasia cases (chapter 6).
Part 4 contains chapters on the quality of consultation in Flanders and a comparison of consultation between LEIF and non-LEIF physicians (chapter 7) and between LEIF and SCEN physicians (chapter 8).
In part 5, we provide an overview of the main findings en discuss them.

Table 1: overview of parts, chapters and data used

	Part 2: Handling euthanasia requests in Belgium		Part 3 LEIF physicians as professional consultants in euthanasia			Part 4: Quality of euthanasia consultations	
	2. Process and outcomes of euthanasia requests	3. Differences in euthanasia attitudes and practices between Flanders and Wallonia	4. Establishing specialized health services for consultation in euthanasia	5. Implementation of LEIF	6. Role and involvement of LEIF physicians in euthanasia	7. Quality of consultation with second physicians in Belgium	8. Evaluation of consultation in Flanders and the Netherlands
Nationwide physician survey	X	X		X		X	
Survey LEIF physicians					X		X
Survey attending physicians who made use of LEIF physicians							X
European Values Survey		X					
SCEN registration							X

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Part II

Handling euthanasia requests in Belgium

Life is pleasant. Death is peaceful. It's the transition that's troublesome.

Isaac Asimov

Chapter 2

Process and outcomes of euthanasia requests in Belgium under the euthanasia act: a nationwide survey

Van Wesemael Y, Cohen J, Bilsen J, Smets T, Onwuteaka-Philipsen B, Deliens L. Process and outcomes of euthanasia requests in Belgium under the euthanasia act: a nationwide survey. Journal of Pain and Symptom Management 2011, in press.

Abstract

Context

Since 2002, the administration of a lethal drug by a physician at the explicit request of the patient has been legal in Belgium. The incidence of euthanasia in Belgium has been studied, but the process and outcomes of euthanasia requests have not been investigated.

Objectives

To describe which euthanasia requests were granted, withdrawn and rejected since the enactment of the euthanasia law in terms of the characteristics of the patient, the treating physician and aspects of the consultation with a second physician.

Methods

A representative sample of 3,006 Belgian physicians received a questionnaire investigating their most recent euthanasia request.

Results

Response rate: 34%. Since 2002, 39% of respondents had received a euthanasia request. Forty-eight percent of requests had been carried out, 5% refused, 10% had been withdrawn and in 23% the patient had died before euthanasia could be performed. Physicians' characteristics associated with receiving a request were: not being religious, caring for a high number of terminal patients and having experience in palliative care. Patient characteristics associated with granting a request were age, having cancer, and loss of dignity, having no depression, and suffering without prospect of improvement as reason for requesting euthanasia. A positive initial position towards the request from the attending physician and a positive advice from the second physician also contributed to having a request granted.

Conclusion

Under the euthanasia act in Belgium, about half of the requests are granted. Factors related to the reason of the request, the position of the attending physician towards the request, and the advice from the second physician influence whether a request is granted or not.

Physicians of different clinical specialties and in various care settings are sometimes confronted with seriously ill patients explicitly requesting physician-assisted suicide or euthanasia for reasons of physical, psychological and/or existential suffering [1][2][3]. This leads to a challenging situation in which physicians have to decide, after careful consideration, whether they will grant or reject such a request. Although physician-assisted deaths (ie euthanasia, physician-assisted suicide, or life-ending without explicit requests by the patient) occur in many countries [4][5][6][7][8][9], euthanasia (ie the administration of lethal drugs by the physician at the explicit request of the patient) is legally permitted only in the Netherlands, Belgium and Luxembourg while physician-assisted-suicide is legally permitted (or tolerated by jurisprudence) only in Switzerland, Oregon, Washington, Montana, the Netherlands and Luxembourg. In most of these countries and states, the law stipulates that a number of conditions need to be met before the physician can proceed with euthanasia or physician-assisted-suicide [10][11][12][13][14]. In Belgium, the patient's request for euthanasia must be written, voluntary, well-considered and repeated. The patient has to be in a medically hopeless situation of persistent and unbearable physical or psychological suffering as a consequence of a serious and incurable medical condition, which cannot be alleviated otherwise. Before proceeding with euthanasia, the attending physician has to consult an independent second physician who must read the medical file, examine the patient and check whether the patient's suffering is unbearable [15]. Unless the attending physician judges that the above-mentioned requirements for due care are met, the request cannot be legally granted. After euthanasia has been carried out, the attending physician must report the euthanasia case to the Federal Control and Evaluation Commission [16][17][18].

There can be numerous reasons why a euthanasia request is not granted. Physicians can decline to grant it based on their personal or moral objections, the patient can die before a final conclusion is reached (which can also be due to the attending physician postponing the decision) and patients can withdraw their request,e.g.when palliative care was successful in alleviating the suffering. It has been demonstrated in previous research that many medical institutions in Belgium apply palliative filter policies, which means that all palliative care options will be tried before the request is considered further [19]. In summary, characteristics related to the condition of the patient, the request itself, the attitudes of the physicians and other circumstantial factors can determine whether euthanasia is granted or not.
Although in Belgium since the enactment of the law, reports and studies have been published on performed euthanasia cases [20][21][22], little is known about the number of euthanasia requests, about how physicians handle these requests and about which factors influence the request and the outcome. Previous research on euthanasia and physician-assisted suicide requests in other countries has focused on patient characteristics and reasons for requesting euthanasia [23][24][25]. Only one study in the Netherlands has investigated influence of the characteristics of the physician and the request itself on the outcome [26]. A better understanding of the outcomes of euthanasia requests in Belgium and what influences them can provide insight into the extent to which the a priori due care requirements of the euthanasia law (process and patient characteristics) are fulfilled but also into the impact of physician characteristics (eg age, experience in palliative care, religion or attitude towards euthanasia) on the outcome of a request.
This study addressed several research questions. Firstly, we assessed what proportion of physicians in Belgium who are likely to be involved in the care of the dying have received a euthanasia request from a patient since the implementation of the euthanasia law in 2002. Secondly, we examined whether or not, and if so which, physician characteristics influence receiving a request. Thirdly, we described the characteristics of the patients whose requests for euthanasia were granted, refused, withdrawn or left without decision, and finally, we

studied patient, physician, process and request characteristics that are associated with a request for euthanasia being granted.

Study design

An anonymous, self-administered questionnaire was sent to 3,006 Belgian physicians by mail in March 2009. The sample only included registered medical practitioners who worked in Belgium, graduated in their specialty at least 12 months before the sample was drawn, and were likely to be involved in the care of dying patients, so specialties for which little or no experience in the care for the dying could be expected, were excluded. The sample comprised the following specialties: general practice, anesthesiology, gynecology, internal medicine, neurology, pulmonary medicine, gastroentereology, neuropsychiatry, psychiatry, cardiology, radiotherapy, and surgery. The sample was stratified for province and specialty and represents a sampling fraction of 9.2%. For each province a random proportional sample was drawn for each specialty from a commercial register because a recent privacy law makes official registers from the National Institute for Health and Disability Insurance (NIHDI) unavailable to researchers. The used register was kept up to date: physicians in the register were contacted every 18 months to check whether the information in the database was still correct. Comparison of the commercial database with data made publicly available by the NIHDI for key variables of province and clinical specialty did not show any significant differences on these variables between the two registers.

A questionnaire with a unique serial number was sent to each physician in the sample. The physicians were instructed in a covering letter to send the questionnaire to an independent lawyer, whose function was to remove the unique serial number from each one, thereby guaranteeing that the investigators could never link completed surveys to a particular patient or physician. In cases of non-response, up to three reminders were sent within seven weeks [27]. No financial incentive was provided. Returning the completed survey was considered as informed consent to participate in the study. The anonymity procedure and study protocol were approved by the Ethical Review Board of the University Hospital of the Vrije Universiteit Brussel.

To assess non-response bias, non-responders were sent a one-page form, asking them for their reasons for not participating and requesting them to fill in two key questions from the original questionnaire. One question was about their attitude to euthanasia and the other asked whether they had ever received a request for euthanasia.

Questionnaire

The pre-structured, eight-page questionnaire with mainly closed-end questions was based on one previously used in the Netherlands [28]. The questions were adapted to make them appropriate for the Belgian legal context and culture and a forward-backward translation was used from Dutch into French for French-speaking physicians. Questions on sex, age, religion, number of years of practice, number of patients cared for in their terminal phase during the past year and training in end-of-life care were incorporated. In the questionnaire, euthanasia was defined as 'intentionally ending the patient's life at his/her explicit request, by the physician'. This definition corresponds to the legal definition of euthanasia in Belgium.

One module of the questionnaire asked whether the physicians had ever received a request for euthanasia during their career and the number of euthanasia requests they had received in the last two years and how many of these were granted. Concerning their most recent euthanasia request, physicians had to answer questions on patient and request characteristics, their initial position towards the request (ie whether they intended to grant the request when the patient

first made it), consultation with a second physician, activities of the second physician, outcome of the request and possible alternative decisions made where a euthanasia request was not granted.

Statistical analysis

A comparison of the response and the sample indicated a slight bias for region: Wallonia was underrepresented and Flanders and Brussels slightly overrepresented in the response. Hence, when presenting frequencies and fitting regression models a weighting factor was used to correct for region, making the data representative for all physicians in the sample. Chi-square tests were performed to compare for physician and patient characteristics. Logistic regressions with the variables significant in the bivariate analyses using both the backward and forward conditional procedures, were performed to produce predictors of receiving and granting a request for euthanasia. The latter was done by expanding the model step by step to see how inclusion of a series of variables in the model influenced the other effects. First, a logistic regression was conducted with only patient characteristics to verify their influence on a request being granted. Then physician characteristics were added to the model. Finally, we added process and request characteristics. Odds ratios and 95% confidence intervals are presented. The analyses were performed using SPSS 17.0 and StatXact 6 (for the Fisher exact tests).

Response rate and response bias

Of the 3,006 questionnaires sent, 149 respondents could not be reached, one physician was sick, one was deceased and 72 were no longer in practice. Of the remaining 2,783 questionnaires, 914 were returned.
Five-hundred and eighty-three physicians replied to the non-response form. Not being involved in the care of dying patients, never responding to questionnaires and having no time to respond to questionnaires were the main reasons for non-response. Physicians who no longer practiced (N=32) or who did not receive the questionnaire (N= 25) were subtracted from the denominator, bringing the final denominator to 2726 and the response rate of the study to 34%.
No significant difference between responders and non-responders was found for the question whether or not the physician had ever received a request for euthanasia. Although both groups overwhelmingly agreed that the administration of life-ending drugs at the explicit request of a patient is acceptable for those with a terminal disease with extreme, uncontrollable pain or other uncontrollable suffering, non-responders were somewhat less likely to agree (87.4% versus 93.0%, $p<0.001$) and were more neutral toward the statement than responders (8.8% versus 4.0%, $p<0.001$).

Receiving a euthanasia request

Of the responding physicians, 48% (weighted n=429) had ever received a euthanasia request and of these, 40% (weighted n=363) of them had received one since the enactment of the euthanasia law (table 1). Physicians older than 36 years and male physicians had received a request significantly more often. Physicians with training in palliative care or who are member of a palliative team had more often received a request (49%) than did those without training (30%). Of the physicians who had cared for more than ten dying patients during the past year, 61% had received a request since legalization, compared with 12% of those who did not care for terminal patients. No significant differences were found between religious and non-religious physicians.

Using a backward stepwise multivariate logistic regression, the characteristics of the physician associated with receiving a euthanasia request were examined (Table 2). Being non-religious, having had training in palliative care or being member of a palliative team were predictors for receiving a euthanasia request. Also, having cared for a higher number of terminal patients in the past year, and being older than 36 years increased the chances of receiving a euthanasia request. The physician's specialty, sex and attitude towards euthanasia were not significant predictors for receiving a request.

Table 1: Characteristics of physicians receiving a request for euthanasia since implementation of the euthanasia law

	N (total respondents)	% received euthanasia request since law*	p-value †
Total	914	39.7	
Sex			
Male	580	43.9	**<0.001**
Female	325	32.8	
Age			
Younger than 36	111	27.4	**<0.01**
36-50 years	324	41.3	ns
51-60 years	320	45.0	ns
Older than 60	133	33.8	ns
Specialty			
Radiotherapy	4	100	**<0.05**
Neurology	11	73.3	**<0.05**
Pulmonary diseases	11	61.0	ns
General surgery	30	49.5	ns
Internal medicine	73	40.3	ns
Gastroenterology	17	45.5	ns
General practice	561	40.5	ns
Anesthesiology	75	37.7	ns
Psychiatry	41	32.2	ns
Neuropsychiatry	12	34.4	ns
Cardiology	28	24.2	ns
Gynecology	45	20.4	**<0.01**
Training in palliative care or member of palliative team			
Training but not a member of palliative team	389	47.5	**<0.001**
Member of palliative team	47	65.7	
No training and not a member of palliative team	460	30.3	
Number of terminal patients cared for in 1 year			
0 patients	202	12.2	**<0.001**
1 to 10 patients	517	46.7	**<0.001**
more than 10 patients	105	61.4	**<0.001**
Religiosity			
Not religious	306	43.1	ns
Religious, specific religion(s)	501	40.0	ns
Religious, but non-specific	96	34.2	ns

Percentages are based on weighed numbers and might not correspond to the unweighted numbers
* Number might not add up to total because of missing cases
† Significance tested with StatXact, Fisher exact test for statistically significant differences between categories vs all other categories within the variables

Table 2: Physician's characteristics associated with receiving a euthanasia request

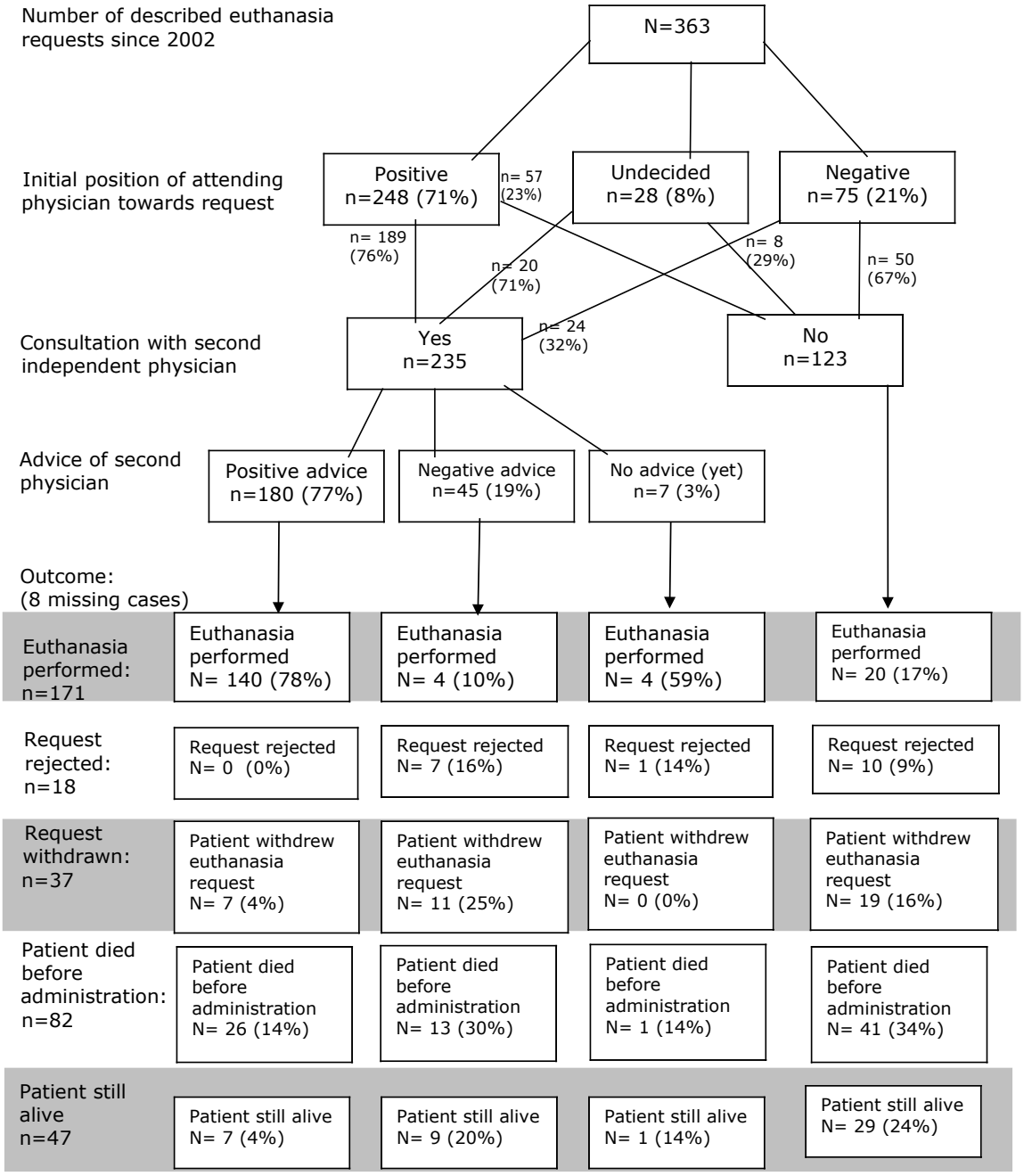
Physician's characteristic	Odds ratio	95% CI	P -value
Not religious (versus religious)	1.45	1.05-2.02	**< 0.03**
Number of terminal patients cared for during last 12 months			
0 patients	1.00	1.00-1.00	**<0.001**
between 1 and 10 patients	4.26	2.785-6.51	**<0.001**
more than 10 patients	7.06	3.988-12.49	**<0.001**
Having had training in palliative care or being member of a palliative team (yes vs no)	1.89	1.37-2.60	**<0.001**
Age			
younger than 36	1.00	1.00-1.00	**<0.001**
between 36 and 50 years	2.42	1.45-4.03	**< 0.01**
between 50 and 60 years	3.06	1.83-5.12	**<0.001**
older than 60	2.55	1.39-4.68	**<0.01**

(N=770, 15.8% missing cases, odds ratios and 95% confidence intervals)
Backward stepwise (conditional) multivariate regression.
Physician's characteristics that were significant in bivariate model but excluded in the regression are: specialty, sex and attitude towards euthanasia.

Outcomes of euthanasia requests: process, patient and physician characteristics

Three hundred and sixty-three most recent euthanasia requests (post-2002) were described in the questionnaire (weighted number, figure 1). In 71% (n=248), the attending physician's initial position towards the request was positive, meaning that he or she had already decided they would probably or certainly grant the request; in 21% (n=75) it was negative, meaning he or she had already decided to probably or certainly refuse the request. Sixty-five per cent (n=235) of the responding physicians consulted an independent second physician about the request and 77% (n=180) of these consultations resulted in a positive advice from the independent physician. Of all requests, 48% (n=171) eventually ended in euthanasia, 5% (n=18) were rejected and 10% (n=37) were withdrawn by the patient. Twenty-three percent (n=81) of the patients died before euthanasia was carried out and 13% were still alive at the end of the study (n=47). Where the second physician had given a positive advice, euthanasia was performed in 78% (n=140) of cases, compared with 10% (n=4) in cases the advice had been negative and 59% (n=4) where an advice had not been given.
In cases where the second physician gave a negative advice, he judged that there was no unbearable suffering (26%, n=12), no medically hopeless situation (31%, n=14), no well-considered request (10%, n=5) or that there were palliative options available (26%, n=12, not in table). Thirty-four percent (n=41) of patients where the advice of a second physician was not sought died before euthanasia could be performed and 17% (n=20) died by euthanasia. For 10 of the 18 patients whose request was rejected, a different end-of-life decision with a possible life-shortening effect was made. Such a decision was made in 23 of the 37 patients who withdrew their request.

Figure 1: Process and outcome of requesting euthanasia in clinical practice in Belgium (within group %)



Numbers may not add up to total due to missing cases. Percentages are based on denominator of previous step.

A euthanasia request was granted significantly less often for those 80 years or older than for younger people; those older than 80 also withdrew their requests more often than did younger people, and instead a non-treatment decision was more often made (Table 3). No requests were granted from patients with a psychiatric disorder and those from patients whose main diagnosis was general deterioration were granted less often compared with those from patients with other diagnoses.
When physicians indicated dyspnea or vomiting as one of the reasons, euthanasia was granted significantly more often than when other reasons were mentioned. The request for euthanasia was granted less often when depression, weariness of life or not wanting to be a burden on the family were indicated as one of the reasons. Requests were also rejected significantly more often when depression was given as a reason.

Table 4 lists the results of a step-by-step expanded multivariate logistic regression model examining patient, physician, process and request characteristics that predict whether a request is granted and performed or not and the influence of these characteristics on each other. A first model only examined the association between granting a euthanasia request and characteristics of the patient: suffering without prospect of improvement as a reason for requesting euthanasia (OR=2.65), experiencing loss of dignity (OR=1.86) and having cancer (OR=2.36) increased the chance of having a euthanasia request granted. Depression as reason for requesting euthanasia (OR=0.26) and being older than 80 years (OR=0.51) reduced the chance. Adding physician characteristics like initial position towards the request and religion to the regression model (Model 2) showed that chances of a request being granted are almost seven times higher when the attending physician is initially positive towards the request. When the attending physician was not religious, the chance of a euthanasia request being granted also increased (OR=1.97). By adding these physician characteristics, the effects of the patient characteristics age, depression and loss of dignity as reasons for the request were no longer significant. In a third model, process and request characteristics were added. A positive advice from the second physician is highly influential in granting a request (OR=20.96). Adding this factor into the model dissipated the effects of the other variablesi.e.religious beliefs of the attending physician and cancer as primary diagnosis and strongly reduced the effect of suffering without prospect of improvement as a reason for the request and that of the initial position of the attending physician towards the request. The initial position of the attending physician continues to play an important role in whether euthanasia is performed or not (OR=4.45).
A step-by-step expanded multivariate logistic regression was also performed to yield predictors for refused requests. A psychiatric diagnosis (OR= 5.42, CI [1.36-21.53]), a diagnosis of general deterioration (OR=16.68, CI [1.82-152.89]) and depression as a reason to request euthanasia (OR=8.18, CI [2.56-26.11]) are patient characteristics associated with refused requests for euthanasia. A neutral or negative initial position of the attending physician is also associated with a refused request.

Table 3: Characteristics of patients who have made a request for euthanasia since the enactment of the law

Patient characteristics	Euthanasia requested	Euthanasia performed	Euthanasia request rejected	Patient withdrew euthanasia request	Patient died before administration	Patient still alive
	N (column %)	Row %	Row %	Row %	Row %	Row %
TOTAL	355* (100%)	48.3	5.0	10.4	23.0	13.2
Gender						
female	171 (48.7%)	44.4	5.8	9.9	22.2	**17.5**
male	180 (51.3%)	52.2	4.4	10.6	23.9	8.9
Age						
< 40 years	13(3.7)	38.5	7.7	7.7	15.4	30.8
40-49 years	26 (7.4)	38.5	3.8	7.7	23.1	26.9
50-59 years	48 (13.7)	54.2	4.2	10.4	18.8	12.5
60-69 years	75 (21.4)	52.0	5.3	8.0	25.3	9.3
70-79 year	113 (32.3)	54.0	3.5	8.0	23.0	11.5
80 years or older	75 (21.4)	**33.3**	8.0	**17.3**	26.7	14.7
Diagnosis†						
cancer	226(63.7)	61.1	2.7	8.4	24.3	17.0
COPD	16 (4.5)	62.5	0.0	12.5	12.5	12.5
MS/ALS	12 (3.4)	33.3	0.0	8.3	25.0	33.3
heart failure	10 (2.8)	20.0	0.0	20.0	50.0	10.0
psychiatric disorder	19 (5.3)	**0.0**	15.8	15.8	**0.0**	**68.4**
general deterioration	25 (7.0)	**16.0**	20.0	8.0	32.0	21.0
other‡	37 (10.4)	32.4	10.8	16.2	13.5	27.0
Reasons for requesting euthanasia §						
suffering without prospect of improvement	252 (71.6)	55.2	2.8	7.1	22.6	12.3
deterioration/loss of dignity	154 (43.9)	55.8	4.5	5.2	23.4	11.0
pain	120 (34.0)	56.7	0.8	7.5	27.5	7.5
general weakness/fatigue	113 (32.2)	52.2	6.2	9.7	24.8	7.1
not wanting to be a burden on family/environment	113 (32.0)	**39.8**	8.0	13.3	22.1	16.8
dependence	78 (22.2)	43.6	1.3	**16.7**	23.1	15.4
tired of living	92 (26.0)	**34.8**	8.7	13.0	23.9	**19.6**
invalidity	50 (14.2)	50.0	4.0	10.0	22.0	14.0

fear of suffocating	46 (13.1)	60.9	0.0	6.5	23.9	8.7
depression	43 (12.2)	**16.3**	**20.9**	11.6	23.3	**27.9**
dyspnea	24 (6.8)	**70.8**	0.0	8.3	20.8	0.0
vomiting	11 (3.1)	**81.8**	0.0	0.0	18.2	0.0
Suffering as most important reason for requesting euthanasia	139 (40.6)	61.2	2.9	5.0	19.4	11.5
written request (N=302)	219 (62.9)	63.0	2.3	5.5	19.6	9.6

* For 8 cases the information on the outcome was missing. Percentages are calculated for valid cases.
† Physicians indicated multiple diagnoses in 11 cases. They were not taken into the table.
‡ other diagnoses include AIDS (1), CVA (7), (beginning) dementia (4) , Parkinson (2), quadriplegia (1), MSA (1), myopathy (1) and not-specified diagnoses (19)
§ more than one answer possible
Significance tested with StatXact, Fisher exact test for statistically significant differences between categories vs all other categories within the variable. Significant values are bold and underlined

Table 4: Factors associated with a request for euthanasia being granted after implementation of the euthanasia law (odds ratios and 95% confidence intervals)

	Model 1* (patient)		**Model 2† (patient + physician)**		**Model 3‡ (patient + physician + process)**	
	Odds ratio	95% CI	Odds ratio	95% CI	Odds ratio	95% CI
PATIENT CHARACTERISTICS						
Being older than 80 years (versus younger)	0.51	**0.28-0.94**	-	-	-	-
One of the reasons for requesting euthanasia						
suffering without prospect of improvement (yes)	2.65	**1.52-4.63**	2.15	**1.19-3.88**	2.21	**1.10-4.44**
depression	0.26	**0.10-0.68**	-	-	-	-
loss of dignity	1.86	**1.12-3.09**	-	**-**	-	-
Having cancer (versus non-cancer)	2.36	**1.34-4.15**	2.19	**1.22-3.95**	-	-
PHYSICIAN CHARACTERISTICS						
Initial position of attending physician towards request						
negative			1.00	1.00-1.00	1.00	1.00-1.00
positive			6.94	**2.99-16.11**	4.45	**1.69-11.74**
undecided			2.89	0.92-9.15	1.98	0.52-7.55
Not religious versus religious			1.97	**1.13-3.43**	-	-
PROCESS AND REQUEST CHARACTERISTICS						
Advice second physician						
positive					20.96	**5.81-64.53**
negative					1.00	1.00-1.00
no advice sought/received					2.29	0.71-7.37

* N=307, 1.9% missing cases
† N=295, 5.8% missing cases
‡ N=287, 8.3% missing cases
Bold: significant
- : eliminated from model via backward stepwise (conditional) multivariate regression
Patient factors that were significant but excluded in model 1 when controlling for other factors: reasons for requesting euthanasiai.e.tired of living. Physician characteristics that were excluded from the model are: age, number of terminal patients cared for, training in palliative care and attitude towards euthanasia. Having a written request was also significant but excluded from model 3 when controlling for other factors.
The category of patients still alive at the end of the study, is not included in the multivariate regression.

This study is the first to describe euthanasia requests and the circumstances in which such requests have been granted, refused, withdrawn or left without decision since the legalization of the Belgian euthanasia law in 2002. We found that almost 40% of responding physicians from specialties likely to be involved in end-of-life care have received a euthanasia request since the enactment of the law. Not being religious, a higher number of terminal patients cared for, having had training in palliative care or being a member of a palliative team and being older than 36 are factors predictive of whether a physician has received such a request. Of the requests described, 48% ended in euthanasia, 23% in the patients dying before euthanasia was carried out and only 5% were actually rejected. A euthanasia request is granted significantly less often when the patient is older than 80 years and when their diagnosis is a psychiatric disorder or general deterioration. Suffering without prospect of improvement as a reason for the request, the positive initial attitude of the attending physician towards the request and a positive advice from the second physician are the most important determinants of a request being granted.

This study is the first to be conducted in both the Dutch- and French-speaking part of Belgium by means of a rigorous sampling and mailing procedure. While a postmortem death certificate survey is more appropriate to assess compliance with due care criteria in actual cases of euthanasia [18], the survey method used in our study was more appropriate to evaluate how physicians handle euthanasia requests. The study also has limitations. First, the low response of 34% makes it difficult to generalize the results, although analyses of the non-response survey indicated that the sample of responders was comparable to the sample of non-responders regarding region and having received a euthanasia request. Non-responders were somewhat less supportive of euthanasia than were responders, indicating a slight response bias. The underrepresentation of Walloon physicians in the responding population might be explained by cultural differences concerning the practice of and attitudes about euthanasia. Previous research has, amongst other differences between the regions, found that Walloon physicians, more than Flemish physicians, consider euthanasia to be a private matter between patient and physician [29]. This could translate into greater reluctance to answer questionnaires about euthanasia.
There may also be a recall bias, especially for requests from more than a year earlier. Furthermore, the information on the circumstances of the euthanasia requests only stems from the physician's point of view.

Reasons for requesting euthanasia are medical, social and psychological, but suffering without prospect of improvement is the most important. This confirms results from studies conducted in the Netherlands [30][26], and is in line with what could be expected considering that the euthanasia laws in both countries specify unbearable suffering as a key due care requirement. Pain is an important reason for requesting euthanasia in over one-third of cases, which is also consistent with previous studies [2][25][24][26]. The survey did not provide information on whether patients requesting euthanasia received palliative care, although a significant proportion of requests were made explicitly to palliative care physicians or physicians with palliative care training. Although trends show improvement, a review on pain in cancer treatment revealed that almost one out of two cancer patients is undertreated for pain [31]. Our study shows that pain was one of the reasons for requesting euthanasia in 44% of cancer patients (albeit usually in combination with other reasons).

We found that only 5% of all requests are actually rejected, which is considerably fewer than in the Netherlands (12%) [26]. This low number of actual rejections in comparison with the proportion of euthanasia acts taking place may indicate that postponing the decision (procrastination) or trying to convince the patient to choose a different option (persuasion) are more acceptable forms of rejection for some physicians. Indeed, almost a quarter of patients

died before euthanasia could be performed (26% in the Netherlands) and a third in cases where the advice of a second physician was not sought. These patients may have been already too close to death when requesting euthanasia, leaving no time to start the decision-making process, but a more likely explanation is that the attending physician waited too long to contact a second physician, in order perhaps to take the time to consider the request or to avoid the subject [32].
Unfortunately, we have no information on the reasons why the attending physicians from our study refused to grant requests, although they may have been influenced by the reasons given by the second physician in cases of a negative advice, such as the lack of unbearable suffering or the availability of palliative options. Other research has shown that in cases of refused requests physicians are not convinced that the patient's suffering is unbearable [26][30][33]. Particularly where the suffering involves psychosocial or existential rather than physical symptoms, physicians seem to find it more difficult to address these requests [3][34]. Our results confirm this: when depression, being tired of living or not wanting to be a burden on the family are reasons for requesting euthanasia, the request is granted less often, whereas it is granted more often when the reasons are vomiting, dyspnea or pain. When a psychiatric disorder is the primary diagnosis, the requests were never granted. Although the Belgian euthanasia law specifically mentions psychological suffering as grounds for requesting euthanasia, it seems that the physicians in our study still associate unbearable suffering more with physical than with psychological symptoms and that they grant a request more easily when there are physical symptoms.

The repeatedly-expressed concern that vulnerable people (older people, disabled people, those with psychiatric disorders) would more easily receive euthanasia is not supported by our data [35]. On the contrary, we found that requests for euthanasia from patients of 80 years and older are granted less often and are withdrawn more often. Requests from patients with a psychiatric disorder were never granted and those from people with general deterioration were granted less often. The chances of receiving euthanasia are lower when depression is one of the reasons for requesting euthanasia and when the patient is 80 years or older. This may be reassuring on the one hand, but may on the downside also be an indication of possible 'discrimination' of certain patient groups in granting euthanasia requests.
Suffering without prospect of improvement, loss of dignity, not being depressed, being younger than 80 and having cancer are predicting factors for having a request granted. However, most of these patient characteristics lose their predicting value when physician and process characteristics are added to our model, implying that the latter have more influence on the decision than the former. This should, however, be understood as follows: patient characteristics (eg age of the patient, depression or loss of dignity as reasons for the request) clearly influence the initial attitude of the attending physician, after which this attitude will strongly determine whether the euthanasia request is granted and will probably determine whether a second physician will be consulted. The second physician's advice confirms that when the patient requirements are fulfilled, then the process can proceed.
Our model shows suffering without prospect of improvement to be the most important patient characteristic influencing whether a request is granted This may be seen as reassuring given that it is a substantive due care requirement in the euthanasia law. Previous research has indeed shown that the patient is the most important source of information in the assessment of unbearable suffering [36] and that unbearable suffering is a more decisive factor for a request being granted than the disease [37].

Finally, our results also show that physicians with training in palliative care or those who are members of a palliative team receive requests for euthanasia more often, and that they do not grant them less often, than those with no palliative care background. This suggests that palliative care does not reduce requests for euthanasia, which is consistent with previous research [1]. It supports the view that euthanasia can be seen as one possible outcome within palliative care in Belgium [38].

Conclusion

Almost 40% of the Belgian physicians from the specialties we selected in our method have received a euthanasia request since the enactment of the law and almost half of these requests were eventually granted. The most frequent reasons for requesting euthanasia are suffering without prospect of improvement, loss of dignity and pain. This last indicates either suboptimal pain control or the failure to relieve all pain with measures accepted by the patient. More than pain, suffering without prospect of improvement remains a decisive factor for the outcome of the request throughout the whole decision-making process. When it is recognized by both physicians reviewing the case, then the euthanasia process can proceed.

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Chapter 3

Differences in euthanasia attitudes and practices between Flanders and Wallonia

Cohen J, Van Wesemael Y, Bilsen J, Smets T, Deliens L. Differences in euthanasia attitudes and practices between Flanders and Wallonia. Submitted.

Abstract

Background
Since 2002, Belgium has a national law legalizing the practice of euthanasia. The law prescribes several substantial due care requirements and two procedural due care requirements, i.e. consultation with an independent physician and reporting of euthanasia to a Federal Control Committee. A large discrepancy in reporting rate between the Dutch-speaking (Flanders) and the French-speaking part (Wallonia) of Belgium led to speculations on cultural differences regarding the euthanasia practice in both regions. This study presents empirical evidence of differences between both regions in attitudes and practice concerning euthanasia

Methods
The Belgian data of the European Values Study were used to compare acceptance of euthanasia of the Walloon and Flemish general public. Data from a large-scale mail questionnaire survey on euthanasia for 480 physicians from Flanders and 305 from Wallonia likely to be involved in the care of dying patients were used to compare differences between Wallonia and Flanders.

Results
The acceptance of euthanasia among the general public was slightly higher in Flanders than in Wallonia.
Walloon physicians held more negative attitudes towards performing euthanasia and towards the reporting obligation than Flemish physicians. They also less often correctly labeled a hypothetical case of euthanasia and less often thought the euthanasia case had to be reported than Flemish physicians.
A higher proportion of Flemish physicians had received and granted a euthanasia request since the introduction of the euthanasia law. In cases of a euthanasia request, Walloon physicians consulted less often with an independent physician. However, an equal proportion of cases with consultation in both regions resulted in euthanasia in. Of all performed euthanasia cases 73% of Flemish physicians and 58% of Walloon physicians indicated having reported it.

Conclusion
There are significant differences between Flanders and Wallonia in practice, knowledge and in attitudes regarding the practice of euthanasia and the legal requirements. These can explain the discrepancy between the low number of reported euthanasia cases from Wallonia and the relatively high number from Flanders. Cultural factors seem to play an important role in the influence of a euthanasia law and the extent to which legal safeguards are followed.

Cultural differences can be an important factor causing differences in health behavior of patients but also of physicians (1)(2)(3)(4)(5). In particular, physicians' compliance to health care guidelines or regulations can be susceptible to cultural determinants.
Belgium makes an interesting case in this respect. As the country currently undergoes a political crisis in which the political representatives of both its language communities fail to find political unison, speculation about cultural differences between Flanders, the Northern Dutch-speaking part making up 56% of Belgium's population, and Wallonia, the Southern French speaking part (44% of Belgium's population), is peaking. Stereotypes –for instance circulating in popular media discourses- depict the Flemish as more individualistic, having a stronger focus on organization, hardworking, and submissive to discipline, as inherent to 'Germanic culture', whereas Walloons are said to be more belonging to Romanic culture and to have a stronger sense of community, but also lack of a predilection for regulation and be less hardworking (6)(7). These stereotypical differences between both regions are a lot less pronouncedly reflected in actual empirical research findings (8)(9)(10)(11).

Also in the medical field, and in particular with regard to end-of-life care, differences between both regions have been subject to speculations about cultural differences (12)(13)(15)(15). This is reinforced by the fact that, while various aspects of health care are a Federal (ie national) matter, Wallonia and Flanders have autonomous responsibility for various health care organizational aspects, such as health promotion and prevention, different aspects of older people care, home care and the coordination and collaboration in palliative care (16). The ministries of health of the different regions and communities decide on the subsidies given to home care and services and health promotion, prevention and education and they also supervise and regulate these matters.
Particularly regarding the euthanasia practice - a practice that is legal in Belgium and subjugate to legal safeguards - there are strong speculations on cultural differences between Flanders and Wallonia. The euthanasia law in Belgium specifies several substantial due care criteria (eg unbearable suffering without prospect of improvement, explicit and repeated request) which have to be met in order for the euthanasia to take place as well as two procedural due care requirements: a second independent physician has to be consulted beforehand to evaluate whether the euthanasia request of the patient can be granted and, once performed, the euthanasia case has to be reported to the Federal Control and Evaluation Committee for Euthanasia (17). It has been found that only about 15% of the euthanasia cases reported to the Federal Control and Evaluation Committee in Belgium had been reported by French-speaking physicians (15). While some have concluded from this that euthanasia is actually a much more frequent practice in Flanders, it is also often assumed that this very large difference does not, in fact, reflect a very large difference in actual practice but rather a reluctance to report euthanasia cases (18). However, previous studies have indicated a tendency towards more performance of euthanasia by Flemish (Dutch-speaking) physicians and more continuous deep sedation by French speaking physicians (19)(20). Patients in the French-speaking community would also more often receive life-prolonging treatment (20). While the statistical power of some of these studies was insufficient to warrant strong conclusions, they seemed to suggest that differences in reporting rates may likely indeed be partly due to actual differences in the extent to which euthanasia is performed. However, it also seems likely that attitudinal differences underlie the large difference in the number of reported cases from both language communities, with suspicions of more covert euthanasia by French-speaking physicians due to their supposed inclination to conform less to regulations. The latter would imply different attitudes and approaches between Dutch- and French-speaking physicians towards the procedural due care criteria included in the prevailing euthanasia law in Belgium, such as the mandatory control beforehand by involving a second independent consulting physician who ascertains that the substantial due care criteria are met (eg request etc), and the mandatory control afterward by officially reporting a case of euthanasia (20).

In a context of increasing accentuation of differences between both language communities and regions, however, it is difficult to distinct constructed myths from actual differences.

This article tries to present empirical evidence from several data collections concerning differences in attitudes and practice concerning euthanasia. It will address the following questions:
1) Do attitudes towards euthanasia of the general population differ between Wallonia and Flanders?
2) Do attitudes towards euthanasia and towards the procedural due care requirements of the euthanasia law differ between physicians from Wallonia and Flanders?
3) Do Walloon physicians receive fewer euthanasia requests from their patients?
4) Do Flemish and Walloon physicians deal differently with euthanasia requests, and if they grant a request do they respect the procedural due care requirements (ie consulting an independent second physician and reporting the euthanasia case) differently?
5) Do Walloon and Flemish physicians have a different notion of euthanasia and of the reporting obligation?

Study design
To answer the research questions, two data sources are used: the Belgian data of the European Values Survey and a large-scale survey of Belgian physicians.

European Values Study (research question 1)
The first data source, answering the first research question, concerns the 2008 Belgian data of the European Values Study. This is a large-scale survey held in 2008 in 47 European countries. In each country, a representative multistage or stratified random sample of the adult population 18 years and older was approached for face-to-face interviewing. More detailed information on the scope of the survey, the selection procedure and data collection procedure can be found elsewhere (21)(22). The questionnaire used in the survey includes several questions about respondents' socio-demographic background, their religious values and orientations, and several attitudes. One question of the questionnaire asks about respondents' acceptance of euthanasia: "Please tell me whether you think euthanasia (terminating the life of the incurably sick) can always be justified, never be justified, or something in between", after which the respondents are asked to give a rating on a scale from 1 (never) to 10 (always). For the purpose of this article we use only the data collected in Belgium, and make a distinction between the respondents from Flanders and those from Wallonia.

Physician survey (research question 2-5)
To answer the second to the fourth research question we use data collected through a large scale physician survey in Belgium. In March 2009, a mail questionnaire was sent to a sample of 3,006 registered medical practitioners who worked in Belgium, graduated in their specialty at least 12 months before the sample was drawn, and were likely to be involved in the care of dying patients based on their specialty. As such, a representative sample was drawn from all general practitioners, anesthesiologists, gynecologists, internists, neurologists, pulmonologists, gastroenterologists, psychiatrists and (neuro)psychiatrists, cardiologists, radiotherapists, and surgeons. The sample was proportionally stratified for province and specialty.
The sampled physicians received a questionnaire with a unique serial number and were instructed in a cover letter to send it to an independent lawyer, in order to guarantee complete anonymity while allowing for the sending of up to three reminders (23). The anonymity procedure and study protocol were approved by the Ethical Review Board of the University Hospital of the Vrije Universiteit Brussel. More information about the design, the mailing procedure, and the non-response survey that was conducted can be found elsewhere (14).

A pre-structured, eight-page questionnaire was developed in Flemish and translated forward and backward into French for use in the French-speaking part of Belgium. The questionnaire was tested with 10 physicians, using cognitive testing. The physicians suggested improved and unambiguous question wording, layout, and routing. Euthanasia was defined in the questionnaire, according to the legal definition of euthanasia in Belgium, as 'intentionally ending the patient's life at his/her explicit request, by the physician'. The questionnaire first assessed the attitudes of physicians towards euthanasia and other end-of-life decisions and towards the euthanasia law and the legal due care criteria of the law. Agreement with each statement was measured on a 5-point Likert scale (strongly agree, agree, neutral, disagree, and strongly disagree). Additionally, a module of the questionnaire asked whether the physicians had ever received a request for euthanasia during their career, the number of euthanasia requests they had received in the last two years, for how many of these they consulted a second physician, how many of these were granted, and how many were officially reported to the Federal Control and Evaluation Committee for Euthanasia. Concerning their most recent euthanasia request, physicians were asked about their initial position toward the request (ie, whether they intended to grant the request when the patient first made it), whether they consulted a second

physician, whether the request was granted, and, if so, whether the euthanasia was officially reported.
The questionnaire also presented the physicians with five hypothetical cases of a patient in the final stage of a lethal disease, who severely suffered. In each case, we varied whether or not the patient explicitly requested life-ending, the drugs administered to the patient, the mode of administration, and the effect of the administration of the act. For each case we asked the physician which label best described the act (euthanasia, palliative/terminal sedation, life-ending without explicit request, intensification of pain and symptom treatment, other), whether they thought it conceivable that they would perform a similar act themselves, whether the act had to be reported to the Federal Control and Evaluation Committee for Euthanasia and whether they would report the act themselves in case they had performed it. More details about the cases can be found elsewhere (24).
Questions on sex, age, religion, number of years of practice, number of patients cared for in their terminal phase during the past year, and training in end-of-life care were also incorporated into the questionnaire.

Statistical analysis
A weighting factor was used to correct for differences in non-response between Flanders and Wallonia. All presented percentages are weighted for this weighting factor. Univariate and bivariate statistics were used to describe differences between physicians from Flanders and Wallonia. Pearson Chi square tests (for differences in proportions) and one-way Anova tests (for differences in means) were used to test for statistically significant differences between Flanders and Wallonia. In order to examine whether the observed bivariate differences between Flanders and Wallonia were not confounded by differences in characteristics between both, multivariate ordinal regressions (PLUM) were performed for the attitudes and multivariate binary logistic regression analyses for the binomial categorical dependent variables for which significant differences were found in the bivariate analyses.

Attitudes of the general public

The European Values Survey 2008 surveyed a total of 791 people from Flanders and 591 from Wallonia (total response for Belgium=69%). The mean score of acceptance of euthanasia was slightly but statistically significantly higher in Flanders (6.96; 95%CI: 6.78-7.13) than in Wallonia (6.61; 95%CI: 6.40-6.83) (One way anova test, p=0.015). An analysis of covariance (ANCOVA) showed that this difference could not be accounted for by the slightly higher degree of religiosity found in Wallonia or other sociodemographic characteristics such as age, gender, and level of attained education.

Attitudes of physicians

The physician survey, conducted nationwide in 2009 in Belgium, obtained responses from 480 physicians from Flanders (response rate 31%) and 305 from Wallonia (response rate 29%). Comparison of the sociodemographic characteristics of the physicians from Flanders and Wallonia in the sample showed no significant differences between both, except that physicians in Wallonia were more often hospital specialists and more often older than 60 (Table 1).

Table 1: description of the responding physicians in Flanders and Wallonia

	Flanders	Wallonia	p-value*
Total number (unweighted)	480	305	/
Specialty			
GP	66.6	57.4	**0.01**
Hospital specialist	33.4	42.6	
Training in palliative care			
No palliative care training	46.1	50.3	0.188
Palliative care training	47.4	41.2	
Palliative care training and member of a palliative care team	6.5	8.5	
Age			
<36	12.5	11.6	**0.034**
36-50	37.5	36.7	
51-60	37.5	31.6	
>60	12.5	20.1	
Sex			
Man	35.0	36.1	0.759
Woman	65.0	63.9	
Religious denomination			
Catholic	50.0	50.0	0.182
Protestant	0.6	2.0	
Other religion/life stance	6.3	7.4	
Religious but no specific denomination	11.1	8.7	
Humanist	14.5	18.8	
Not religious, no specific life stance	17.4	13.1	
Number of dying patients cared for in the last year			
0	22.3	24.1	0.772
1 to 10	64.9	62.2	
> 10	12.8	13.7	

**: Pearson chi square*

Flemish and Walloon physicians differed in their attitudes towards euthanasia in general: Walloon physicians were more often in no circumstances prepared to administer lethal drugs, would more often rather perform sedation than administer lethal drugs, more often agreed that good palliative care prevents most requests for euthanasia, more often agreed that a physician should always strive to preserve life, and less often agreed that euthanasia can be a part of good end-of-life care (Table 2).

In terms of attitudes towards the existing euthanasia law, Walloon physicians significantly more often believed that it has hindered the further development of palliative care than Flemish physicians, but also less often indicated to be sufficiently informed about the existing law. Flemish physicians more often than Walloon physicians felt that the existing law should be changed to include minors.
In terms of attitudes towards the due care criteria of the law, Walloon physicians were less favorable than Flemish physicians towards the reporting obligation (ie they more often believed that euthanasia was a matter between physician and patient in which a reporting committee has no affairs and less often felt that reporting contributed to a more careful practice) and towards the obligation to consult a second physician (ie they less often believed consulting a second physician in case of a euthanasia request was useful and less often felt it contributed to a more careful practice).

Table 2: Attitudes of physicians towards euthanasia in Flanders and Wallonia

	Flanders	**Wallonia**	**P-value***
General attitudes towards end-of-life decisions			
Everyone has the right to decide about their life and death	70.3	74.3	0.214
The administration of life-ending drugs at the explicit request of a patient is acceptable for patients with a terminal disease with extreme uncontrollable pain or other uncontrollable suffering.	92.3	86.9	0.141
If a terminally ill patient suffers unbearably and is not capable of making decisions on their own, the physician (together with the team of caregivers) should be able to decide to administer life-ending drugs.	55.0	62.0	0.223
I am in no circumstances prepared to administer drugs to hasten death at the explicit request of a patient.	**15.0**	**25.9**	**<.001**
Sufficient availability of palliative care prevents almost all requests for life-ending	**49.6**	**51.8**	**0.018**
Life-ending on request can be part of good end-of-life care	**81.8**	**64.5**	**<.001**
I am more willing to perform continuous deep sedation on request than to administer life-ending drugs on request	**47.7**	**59.4**	**<.001**
If necessary, I would administer pain medication, even if this medication would hasten the patient's death	96.1	96.8	0.162
In all circumstances, physicians should strive to preserve the life of their patients, even if patients ask to hasten their death	**8.0**	**14.8**	**<.001**
Attitudes towards the existing euthanasia law			
Euthanasia should be legal for minors who can value their interests	**51.6**	**43.3**	**0.003**
Euthanasia should be legal for patients who have become incompetent (e.g. due to dementia) when they have an advance directive	81.8	74.1	0.406
The euthanasia law contributes to the carefulness of	68.6	61.5	0.168

physicians' medical behavior at the end of life.			
The euthanasia law impedes the further development of palliative care.	**8.8**	**11.9**	**0.030**
I am sufficiently informed about the content of the euthanasia law	**48.9**	**37.6**	**0.004**
Attitudes towards the legal procedural safeguards			
Attitudes regarding consultation of second physician			
Consulting with a second physician is useful in every case of euthanasia request	**85.2**	**76.5**	**0.031**
In order to give an advice as second physician in a euthanasia request, one has to have followed a special training	53.8	55.6	0.503
Consulting a second physician contributes to the careful practice at the end of life	**85.9**	**72.3**	**<.001**
Attitudes regarding societal control			
Euthanasia is a private matter between patient and physician that does not need to be controlled by the Control and Evaluation Committee.	**19.6**	**37.5**	**<.001**
Societal control over the euthanasia practice is necessary.	71.3	65.6	0.336
Reporting euthanasia cases contributes to the carefulness of physicians' medical behavior at the end of life.	**71.0**	**54.7**	**<.001**

Presented percentages are the percentage answering agree or strongly agree to the statement.
*p-values: Jockheere-Terpstra test testing differences in rank between Flanders and Wallonia

[A multivariate ordinal regression (PLUM) was performed to examine whether bivariate significant differences between Flanders and Wallonia were due to differences in characteristics of Flemish and Walloon physicians (cfr Table 1). Controlling for these characteristics, however, all differences remained significant.]

Receiving euthanasia requests

The proportion of physicians ever having received a euthanasia request in Wallonia and Flanders did not differ significantly. However, a significantly higher proportion of Flemish physicians had received a euthanasia request from one or more of their patients since the introduction of the euthanasia law (Table 3).

Handling euthanasia requests

While Walloon physicians were initially not less often positive towards granting their last request received since the euthanasia law, they had less often consulted a second physician. In the cases in which a second physician was consulted an equal proportion in Flanders and Wallonia judged the due care criteria to be met and the case to qualify for euthanasia and in an equal proportion the euthanasia was carried out. However, of all euthanasia requests (not only those where a second physician was consulted) a higher proportion eventually resulted in euthanasia in Flanders compared to in Wallonia. Walloon physicians more often reported that the patient deceased before the euthanasia could be carried out or that the patient was still alive. Of all performed euthanasia cases 73% of Flemish physicians and 58% of Walloon physicians indicated having officially reported the case to the Federal Control and Evaluation Committee for Euthanasia (Table3).

Table 3: Receiving and handling euthanasia requests

	Flanders (n=480)	Wallonia (N=305)	P-value
Ever received request (%)	50.9	42.8	0.084*
Average number of requests last 24 months (range)	0.72 (0-50)	0.70 (0-25)	0.874†
Average number of requests for which second physician was consulted last 24 months (range)	**0.52 (0-50)**	**0.21 (0-6)**	**0.029†**
Average number performed euthanasia cases last 24 months (range)	0.29 (0-40)	0.13 (0-3)	0.133†
Average number euthanasia cases reported last 24 months (range)	0.24 (0-40)	0.08 (0-3)	0.129†
Received a request since euthanasia law; percentage of total (number)	**44.0 (149)**	**34.7(79)**	**0.012***
↓	↓	↓	
Initial reaction: (probably) not grant request	22.6	25.3	0.738
Consulted second physician regarding request	**73.0**	**50.0**	**0.001**
↓	↓	↓	
Second physician judged case to qualify for euthanasia	75.7	76.3	0.979
↓	↓	↓	
Euthanasia performed	78.5	79.1	0.999
Percentage euthanasia performed of all requests since euthanasia law	**51.2**	**37.9**	**0.035**
↓	↓	↓	
Euthanasia officially reported to Committee	73.1	57.9	0.102

*: pearson Chi² testing differences in distribution between Flanders and Wallonia
†: Student t-test testing differences in mean between Flanders and Wallonia

Labeling and reporting of hypothetical cases

Five hypothetical cases of end-of-life decisions were presented to all physicians: a case of palliative sedation, a case of life-ending of an incompetent patient without there being an explicit request by the patient, a case of euthanasia performed with neuromuscular relaxants, a case of intensified pain and symptom alleviation, and a case of euthanasia performed with opiates. No significant differences between Flemish and Walloon physicians were found in the proportion answering that they can imagine ever practicing the different decisions (Table 4). Walloon physicians significantly less often thought the euthanasia case performed with neuromuscular relaxants needed to be officially reported as a euthanasia case, but on the other hand significantly more often thought the palliative sedation case and the case of life-ending without an explicit patient request needed to be officially reported as a euthanasia case. These differences are also reflected in the proportion that would actually report the case.

The euthanasia case and the palliative sedation case were more often correctly labeled by the Flemish physicians than by the Walloon physicians. In a multivariate logistic regression analysis, the lower actual reporting intention of Walloon physicians for the euthanasia case could not be explained entirely by the more frequent incorrect labeling of the case by Walloon physicians (not in table).

Table 4: labeling of and assessing hypothetical cases

	Case 1 (sedation)		Case 2 (Life-ending without request)		Case 3 (Euthanasia with neuromuscular relaxant)		Case 4 (Intensified pain alleviation)		Case 5 (euthanasia with opiates)	
	Fla	Wall	Fla	Wall	Fla	Wall	Fla	Wall	Fla	Wall
Would ever practice?										
yes	77.7	80.8	82.6	80.6	57.1	53.8	88.5	86.3	73.9	78.3
Needs to be reported legally?										
no	**66.9**	**60.8**	**61.7**	**58.7**	**6.5**	**23.6**	71.3	69.0	56.8	57.1
yes	**9.0**	**16.0**	**10.9**	**17.7**	**85.6**	**59.9**	10.3	14.1	19.3	21.3
don't know	**24.1**	**23.3**	**27.4**	**23.6**	**8.0**	**16.5**	18.3	16.9	23.9	21.6
Would actually report										
yes	**12.1**	**21.1**	**14.6**	**20.7**	**83.7**	**62.1**	14.1	18.1	23.5	26.3
Labeling										
palliative/terminal sedation	**84.4***	**69.6***	31.7	30.2	**5.4**	**13.6**	21.5	27.1	36.3	37.3
Life-ending without explicit patient request	**1.4**	**2.8**	17.1*	16.3*	**2.6**	**4.2**	0.9	1.4	1.3	2.5
Euthanasia	**0.0**	**0.0**	3.9	7.6	**88.6***	**70.4***	9.5	11.3	17.8*	21.1*
Pain and symptom alleviation with possible life-shortening effect	**10.9**	**20.6**	45.0	40.6	**1.9**	**9.1**	66.0*	59.1*	40.9	34.9
other	**3.4**	**7.1**	2.4	5.2	**1.5**	**2.8**	2.2	1.0	3.7	4.3

Bold and underlined: statistically significant ($p<0.05$) difference between Flanders and Wallonia (tested with Pearson Chi^2)
*: correct label

Case description:

Case 1 Palliative/terminal sedation

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

Case 2 Life-ending without patient request

Patient is 73 year old and has an inoperable oesophageal carcinoma with extensive metastasis. Patient is unconscious and can no longer communicate, but suffers obviously. Patient has only a few more days to live. Patient's suffering can hardly be kept under control with a morphine pump and the family can no longer bear to watch the suffering. It is decided to administer morphine via infusion. The dose is doubled every 12 hours. In addition, valium is added to the infusion. Patient dies 24 hours after the infusion is started.

Case 3 Euthanasia 1: using a neuromuscular relaxant

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

Case 4 Intensified pain alleviation

Patient is 73 years old and has an inoperable oesophageal carcinoma with extensive metastasis. Patient is weary and has pain over the whole body. Patient has only a few more days to live. Patient's pain is treated with morphine patches, but they alleviate insufficiently. Patient has several times explicitly requested the physician to

end his/her life. It is decided to administer morphine via a pump. The dose is gradually and proportionally raised. Patient dies 10 hours after the morphine pump was started.

Case 5 Euthanasia 2: using morphine

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

This study indicates several differences in terms of euthanasia attitudes and practices between the Dutch speaking region of Flanders and the French speaking region of Wallonia. The acceptance of the practice of euthanasia was not very different between both regions, both in the general public and among physicians, with a somewhat higher acceptance found in Flanders. However, larger differences emerged in the proportion of physicians receiving a euthanasia request since the euthanasia law (a larger proportion of physicians did so in Flanders) and in particular in the attitudes and actual practices regarding the due care criteria of the law. Flemish physicians appeared to have a better notion of euthanasia and the legal obligations of the euthanasia law, and Walloon physicians were both more reluctant and less inclined to consult a second physician and officially report the euthanasia case.

This study was the first to allow a systematic comparison between Flanders and Wallonia in terms of attitudes towards and practice with regard to euthanasia. In doing so it sheds light over a fierce and long ongoing discussion that has hitherto been merely speculative. The strengths and limitations of the European Values Study have been extensively documented elsewhere (21). Its most important limitation is perhaps that the description of euthanasia does not conform the legal definition in Belgium that was used in the physician survey. The physician survey used for this study comprised a representative sample of physicians in Flanders and Wallonia who were potentially involved in the care for dying patients. In using descriptive questions instead of value laden terms, attitudes and practices with regard to euthanasia could be examined in a neutral way avoiding confusion. Thorough forward-backward translation and cognitive testing of the questionnaires minimizes differences in interpretation of questions between Flemish and Walloon physicians, although cultural differences in interpretations of terms and descriptions can not be ruled out. Further limitations include a low response percentage in both regions, making it difficult to generalize the results to all physicians, and a possible recall bias, particularly for the description of the requests from more than a year earlier.

The results of our study refute some parts and confirm other parts of the speculations as to differences in attitudes and practices regarding euthanasia between Flanders and Wallonia.

Our study did not find any large differences between both regions in terms of the acceptance by the general public or by physicians of euthanasia as a possible decision for suffering and incurable people, but did find a higher reluctance among Walloon physicians to actually perform it. While the difference in public acceptance of euthanasia between Flanders and Wallonia is small, significantly more Flemish physicians have been confronted with euthanasia requests since the euthanasia law was adopted. The latter is thus likely not the result of a difference in attitudes towards euthanasia, but it can, speculatively, be attributed to differences between both regions in the patient-physician trust relation. The extent to which the general public and physicians have been informed and are aware of the existing euthanasia regulation might also play a role here. Walloon physicians in our survey more often indicated that they were not sufficiently informed about the euthanasia law. Dissemination of information about euthanasia probably occurs more often in Flanders due to the presence of the Life End Information Forum (LEIF) since 2003, which aims to inform and train physicians in end-of-life care issues and particularly in the due care requirements and practice of the euthanasia law (25). Also, with the media completely separated in Belgium and their content fundamentally directed towards viewers within the own region, coverage regarding euthanasia seems to have been more present in Flanders than in Wallonia (26). Over the past years, the topic has received ample attention in the northern part of the country in the form of documentaries, news coverage about famous Flemish famous persons receiving euthanasia, and about the extensive research conducted in Flanders on euthanasia (27).

Physicians in Flanders and Wallonia largely accepted the use of lethal drugs in a patient who is suffering severely (respectively 92% and 87%). However, when it came to attitudes towards actually performing the euthanasia, Walloon physician significantly more often indicated that they would never perform euthanasia themselves, more often indicated that they would rather perform sedation over euthanasia, and also more often indicated that it is a physician's duty to always preserve life. Interestingly, they also less often felt that euthanasia can be a part of good end-of-life care.
These differences in attitudes towards performing euthanasia are also reflected in the fact that 38% of Walloon physicians receiving a request since the euthanasia law as compared with 51% of their Flemish counterparts granted the last euthanasia request they received. The lower proportion of physicians receiving a euthanasia request and the lower proportion of physicians who received a request actually granting that request indicate that the low fraction of all reported euthanasia cases in Belgium coming from French speaking physicians is actually also to a considerable extent due to differences in the practice of euthanasia, and not merely the result of a lower reporting rate.

Differences between Walloon and Flemish physicians were, however, also particularly large regarding the attitudes towards the prevailing law and the attitudes and actual practices regarding the due care criteria specified in the law. Walloon physicians less often than their Flemish counterparts indicated that consulting a second physician in case of a euthanasia request was useful and considerably less often felt it would contribute to a careful practice. These attitudes also translated in the way they handled euthanasia requests by their patients: only half of the Walloon physicians as compared with 73% of the Flemish physicians consulted a second physician in case of a request. The absence of a service like LEIF - providing for specially trained physicians for euthanasia consultations- in Wallonia at the time of the study, might account for the low consultation rate. Interesting to note is that when a second physician was consulted the content and outcome of this consultation process was very similar in both regions.
In terms of the reporting obligation, the other procedural due care requirement of the euthanasia law, Walloon physicians considerably more often than their Flemish counterparts indicated that euthanasia was a matter between patient and physician in which a control and evaluation committee need not interfere and considerably less often agreed that the reporting contributes to a more careful practice. As noted by others, it thus seems that culturally determined attitudes towards legal evaluation of medical practices differ between the two regions (14)(28). Again, these attitudes also translate in a somewhat lower actual reporting rate. In addition to these different attitudes towards the usefulness of reporting euthanasia cases, Walloon physicians also clearly seemed to have less understanding of which (hypothetical) cases need to be reported and which do not, and this lower understanding did not seem to be entirely due to their lower accuracy in correctly labeling a case as euthanasia.

Culturally, Flanders might lean more towards the Netherlands, among other things regarding the need to regulate matters and follow rules (29). This would explain why Flemish physicians have in particular more positive attitudes towards the legal due care requirements than Walloon physicians.

Conclusion
We started out by noting that only 15% of all officially reported euthanasia cases come from French speaking physicians, while these care for roughly about 40 percent of dying patients. This has given rise to speculations about differences between Flanders and Wallonia in euthanasia practices, with the practice believed to actually be much more frequent in Flanders. Others have suggested that, as a result of the cultural differences between both regions, Walloon physicians are less inclined to adhere to the legal safeguards such as consulting a second physician and reporting the euthanasia case. Our study found truth in both positions. Walloon physicians less often grant a euthanasia request to their patients, but they also seem

less inclined to adhere to legal safeguarding. Somewhat worrisome is that Walloon physicians also have a less adequate knowledge of what cases can be labeled euthanasia and in addition to that also of what cases need to be reported to the Federal Control and Evaluation Committee for Euthanasia. It seems warranted, based on these findings, to develop information campaigns in Wallonia to better inform physicians (and patients) about the euthanasia law, as that seems to have been done more extensively in Flanders. More in general, our findings seem to suggest that the influence of a euthanasia law in a society and the extent to which legal safeguards are followed are differentiated according to the surrounding culture, and that such might be different in countries with a surrounding Romanic culture than those with a Germanic culture.

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Part III

LEIF physicians as professional consultants in euthanasia

To die proudly when it is no longer possible to live proudly. Death of one's own free choice, death at the proper time, with a clear head and with joyfulness, consummated in the midst of children and witnesses: so that an actual leave-taking is possible while he who is leaving is still there.

Friedrich Nietzsche - *Expeditions of an Untimely Man*

Chapter 4

Establishing specialized health services for professional consultation in euthanasia: experiences in the Netherlands and Belgium

Van Wesemael Y, Cohen J, Bilsen J, Onwuteaka-Philipsen BD, Deliens L. Establishing specialized health services for professional consultation in euthanasia: experiences in the Netherlands and Belgium. BMC Health Service Research 2009, 9: 220.

Abstract

Background

The Netherlands, Belgium, and Luxembourg have adopted laws decriminalizing euthanasia under strict conditions of prudent practice. These laws stipulate, among other things, that the attending physician should consult an independent colleague to judge whether the substantive criteria of due care have been met. In this context initiatives were taken in the Netherlands and Belgium to establish specialized services providing such consultants: Support and Consultation for Euthanasia in the Netherlands (SCEN) and Life End Information Forum (LEIF) in Belgium. The aim of this study is to describe and compare these initiatives.

Methods

We studied and compared relevant documents concerning the Dutch and Belgian consultation service (eg articles of bye-laws, inventories of activities, training books, consultation protocols).

Results

In both countries, the consultation services are delivered by trained physicians who can be consulted in cases of a request for euthanasia and who offer support and information to attending physicians. The context in which the two organisations were founded, as well as the way they are organised and regulated, is different in each country. By providing information on all end-of-life care matters, the Belgian LEIF seems to have a broader consultation role than the Dutch SCEN. SCEN on the other hand has a longer history, is more regulated and organised on a larger scale and receives more government funding than LEIF. The number of training hours for physicians is equal. However, SCEN-training puts more emphasis on the consultation report, whereas LEIF-training primarily emphasizes the ethical framework of end-of-life decisions**.**

Conclusions

In case of a request for euthanasia, in the Netherlands as well as in Belgium similar consultation services by independent qualified physicians have been developed. In countries where legalising physician-assisted death is being contemplated, the development of such a consultation provision could also be considered in order to safeguard the practice of euthanasia (as it can provide safeguards to adequate performance of euthanasia and assisted suicide).

Background

While physician-assisted suicide is regulated in Oregon, and Washington, the Netherlands, and Luxembourg and is legally performed in Switzerland since 1990 [1][2][3], there are only three countries in the world where euthanasia is legal: the Netherlands and Belgium adopted a law in 2002 [4][5] and Luxembourg became the third country to do so on March 16th 2009 [6]. All three laws stipulate substantive and procedural criteria that must be met for euthanasia to be legally performed. The substantive criteria require, among other things, that the patient's request must be voluntary, well-considered, repeated, and not the result of any external pressure; that the patient must be in a medically futile state of constant and unbearable physical or psychological suffering which cannot be alleviated, and is the result of a serious and incurable condition caused by illness or accident; that the physician must fully inform the patient about his/her health condition and prospects (diagnosis and prognosis); and that physician and patient must arrive at the conclusion that there is no reasonable prospect of improvement in the patient's situation. The procedural criteria consist of mandatory notification of the euthanasia case to the official review committee [7], and consultation of a colleague by the attending physician, hereafter called the consultant, who is independent or impartial from both the patient and the attending physician [4], and competent to judge the patient's condition. This consultant must read the medical file and examine the patient in order to judge whether the substantive criteria have been met,i.e.judge the serious and incurable nature of the condition, ascertain that the patient's physical or psychological suffering is constant, unbearable, and without prospect of improvement, and that the patient's request was voluntary, well-considered, and repeated (in Belgium and Luxembourg the law only prescribes this in patients not expected to die in the near future). The Dutch law also stipulates that the consultant should conclude that there are no reasonable alternatives [5]. The consultant must make a written report regarding his or her conclusions.
Consultation in the case of a euthanasia request, as defined by the laws on euthanasia, is very different from an informal discussion between physicians which might occur in other kinds of end-of-life decision-making. Given the seriousness and irreversibility of euthanasia, the consultant has to determine whether the substantive legal requirements of due care are met, and the judgement of the attending physician was made with due care. The consultation of a second physician in euthanasia requests is intended to build a control mechanism into the procedure and prevent unwarranted euthanasia cases. It is also intended to monitor and safeguard the quality of the practice of euthanasia.

The laws in all three countries stipulate that the consulted physician must be independent, impartial and competent to judge the pathology of the patient. However, the consultant is also expected to judge aspects such as existential suffering and feelings of hopelessness, which are more inherent to the final stage of life than to the patient's pathology [8][9][10]. Additional skills therefore seem warranted for a consultant. Ideally, the consultant is someone who does not a priori object to euthanasia, and has a certain amount of experience with or knowledge of end-of-life care and/or euthanasia. Finding such an independent consultant may be difficult for a physician confronted with a euthanasia request. In this context initiatives were taken, in the Netherlands and in Belgium, to establish specialized services to provide such consultants. While the Dutch and the Belgian laws [11] and the notification procedures of euthanasia in both countries have been extensively described and compared elsewhere [7], no studies have described the function and functioning of these specialized consultant health services within the context of a law on euthanasia. This paper aims to describe such specialized health services as established in the Netherlands ('Support and Consultation on Euthanasia in the Netherlands',i.e.SCEN) [12] and in Belgium ('Life End Information Forum',i.e.LEIF) [13]. LEIF is a Flemish initiative and hence in principle only available in the Dutch-speaking part of Belgium; in the French-speaking part a similar, albeit less elaborate initiative has been developed.

The SCEN and LEIF projects will be described and compared in terms of their development, aims, tasks, functioning and organisation.

Methods

We studied and compared relevant documents concerning SCEN and LEIF. To obtain an overview of the development, aims, tasks, functioning and organisation of SCEN, the evaluation report about the implementation and effects of SCEN was studied [14] as well as the results of the annual written inventory of activities of SCEN physicians from 2004 to 2006 [15][16][17]. Additionally, the training book for SCEN physicians [18], the checklist used by SCEN to draw up the consultation report, the protocol used as a guideline for the consultation procedure [19] and the website of the Royal Dutch Medical Association [20] were explored as information sources. Information on the Life End Information Forum in Flanders was acquired through the LEIF website [21], the bye-laws, the LEIF magazine [22], publications concerning LEIF [13][23][24] and the training folders the physicians receive while undergoing training. Furthermore, because there is relatively less written information available about LEIF than about SCEN, an open interview was conducted with the director and training moderator of LEIF to complement the collected information. The persons consulted for information about SCEN and LEIF were notified that their contribution would be used for a comparing paper and they consented to this.

Development

SCEN and LEIF were established in differing contexts (Table 1). In the Netherlands, where euthanasia had already been taking place without prosecution for more than a decade [8][25], the Royal Dutch Medical Association and the Association of General Practitioners wanted to professionalize the consultation process and thus make physicians take responsibility for the quality of the practice. They initiated a pilot project in Amsterdam (Support and Consultation on Euthanasia in Amsterdam, SCEA) in 1997 and extended it to the rest of the country in 1999, after an evaluation of its implementation [25]. In Belgium, the legalisation process of euthanasia was much shorter and enjoyed less support from associations of health care professionals [26]. LEIF was established in February 2003, after the euthanasia law had come into effect, by individual professionals with experience in palliative care and by the association 'Right to Die with Dignity'. Their aim was twofold: to create a service that could refer people to the right health care professionals in end-of-life matters, and to increase physicians' knowledge about palliative care and euthanasia through training programs.

Table 1: development and foundation of LEIF and SCEN

Development & Foundation	LEIF	SCEN
Initiators	Initiative of individuals with experience in end-of-life care and the pluralistic association 'Right to Die with Dignity'*	Initiative of the Royal Dutch Medical Association and the Association of General Practitioners †
Year of founding	In 2003, 6 months after the euthanasia law *	In 1997, before the euthanasia law ‡
Covering region	Provided for the 6 provinces in Flanders*	First a pilot project in Amsterdam (SCEA) in 1997, since 1999 in the rest of the country ‡

* Source: Interview with the director and training moderator of LEIF and Distelmans W: **LEIF: het LevensEinde InformatieForum (LEIF: the Life End Information Forum)**. *Neuron* 2008, **13 (3)**:144-146.
† Source: http://knmg.artsennet.nl
‡ Source: Onwuteaka-Philipsen B, van der Wal G: Support and consultation for general practitioners concerning euthanasia: the SCEA project. *Health Policy* 2001, 56:33-48.
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Aims and tasks

SCEN and LEIF were both initially developed to provide independent and competent second physicians as consultants in euthanasia requests, as required by law (Table 2); these physicians are however also able to provide information and support concerning euthanasia outside the context of consultation. The scope of LEIF is broader than that of SCEN, as its aim is also to provide consultation in other end-of-life decisions, including palliative care, to other physicians as well as to patients, and to provide the wider public with information about euthanasia and other end-of-life matters.

Table 2: aims and tasks of LEIF and SCEN

Tasks	LEIF	SCEN
Tasks	• Provide information and support about euthanasia to physicians, patients and the wider public* • Provide consultation to physicians in euthanasia requests * • Provide consultation to physicians in other end-of-life decisions*	• Provide information and support about euthanasia to physicians, † • Provide consultation to physicians in euthanasia requests †
	Based on the law, when doing a consultation in a euthanasia request, the LEIF physicians has to ‡: • read the medical file • examine the patient • ascertain that the physical or psychological suffering is persistent and unbearable and cannot be relieved • make a written report of the findings	Based on the law, when doing a consultation in a euthanasia request, the SCEN physician has to §: • see the patient • be convinced that the request is voluntary and well-considered • be convinced that the suffering is hopeless and unbearable • inform the patient about his/her situation and prospects • be convinced that there is no reasonable other solution • make a written report on their judgement of the due care criteria

* Source: interview with the director and training moderator of LEIF
† source: http://knmg.artsennet.nl
‡ Source: Law concerning euthanasia May 28 Wet betreffende euthanasie, 28 mei 2002 . *Belgisch Staatsblad 2002 juni 2002 [Belgian official collection of the laws June 22 2002]* 2002, 2002009590
§ Source: Termination of Life on Request and Assisted Suicide (Review Procedures) Act April 1 Wet toetsing levensbeeindiging op verzoek en hulp bij zelfdoding 1 april, 2002 .

Functioning and organisation

SCEN or LEIF physicians must have at least five years of experience as a physician, have experience in the field of euthanasia, be skilful in consultations, and must not be a priori opposed to euthanasia as this would preclude objective consultation [20] (Table 3). Both organisations offer different training modules of roughly 23 hours given by experts, spread over several weeks, on subjects such as the performance of euthanasia, communication with patient and attending physician, and palliative care. SCEN employs actors to provide training in communication skills and lays emphasis on the consultation report, while LEIF focuses on the ethical framework of end-of-life decisions. Both SCEN and LEIF organise group meetings, called 'intervisions', where physicians can discuss concrete problems and cases with colleagues.

Table 3: functioning and organisation of SCEN and LEIF

Functioning & Organisation	LEIF	SCEN
Selection criteria	• 5 years experience in practice * • experience with euthanasia* • skilful in consultations* • not being fundamentally against euthanasia*	• 5 years experience in practice † • experience with euthanasia or physician-assisted death (PAD) † • skilful in consultations† • not being fundamentally against euthanasia† • write a motivation letter†
Training	24 hours spread over 5 modules in 28 weeks Content of modules ‡: • general introduction • end-of-life care (laws of patient rights, palliative care and euthanasia; palliative practice) • context of the LEIF physician and the other caregivers • euthanasia in practice • communication of the LEIF physician Intervisions ‡ • Group meetings per province • twice a year • to discuss cases	22.5 hours spread over 3 days in 5 weeks Content of modules §: • tasks, duties and role of the consultant • communication and emotions around euthanasia • alternative possibilities and the final advice (the consultation report, suffering, palliative care) Intervisions † • Group meetings per district • 3 to 4 times a year • to air problems and to monitor the quality of consultation
Organisation	Comes under the non-profit organisation End-of-life care Academy and has 1 central secretariat for Flanders and Brussels *	Comes under a department of the Royal Dutch Medical Association and is subdivided in 23 districts throughout the Netherlands. There is a consultant network per district †
Contact	One central telephone number at LEIF secretariat, permanently available. LEIF physicians can also be contacted directly ‡	One central telephone number per district, during office hours †
Consultations	Work with guidelines received during training and use the registration form of the Federal Control and Evaluation Committee as a checklist for the criteria of due care *	Follow a written consultation protocol and have a checklist for writing the report
Expenses	No standard compensation is provided. LEIF physicians sometimes charge the price of a normal consultation *	A standard compensation of 280€ is provided via the health insurance of the patient to the SCEN physician after the SCEN physician files a report ||
Control	A guidance group, consisting of medical doctors, academics, ethics, experts in palliative care, nurses and actors, acts as a sounding board for LEIF ‡	An advice council, consisting of medical doctors, academics, a medical advisor and the project leader of SCEN, guards the objectives of the SCEN program †
Support	No more direct financial support after 2007¶	Annually 1.000.000€ support from the Dutch government ||

* Source: interview with the director and training moderator of LEIF
† Source: http://knmg.artsennet.nl
‡ Source: www.leif.be
§ Source: overview of the KNMG training for SCEN physicians, KNMG, November 2008
|| Source: Information obtained by email from the district coordinator of SCEN
¶ Source: Information obtained by email from the LEIF secretariat

There are currently 590 SCEN physicians, corresponding to one per 27500 inhabitants [27] or one per 112 physicians in the Netherlands. At first SCEN training was only offered to general practitioners but in 2007 it was also made available to specialists and nursing home physicians. Now there are 94 specialists and 53 nursing home physicians (not in table) [20] who have followed all five training modules organised by the Royal Dutch Medical Association. In Belgium, there are 161 LEIF-physicians (111 GPs and 50 specialists),i.e. one per 44800 inhabitants [28] or one per 177 physicians [29] in Flanders. These physicians have followed the minimum requirement of at least two modules (including the introductory module) (not in table).

When physicians require a SCEN or LEIF consultant, they can contact the organisations by telephone and a consultant is assigned to them. In the Netherlands there is a telephone number per SCEN district, while for Flanders there is one central number at the LEIF secretariat. However, LEIF physicians can also be contacted directly by the attending physician. After having discussed the case with the attending physician on the phone, both SCEN and LEIF physicians follow the directions as stated in the euthanasia law [4][5]. SCEN physicians can follow a consultation protocol and a checklist as a guideline. LEIF has no official consultation protocol but provides similar guidelines as SCEN during training sessions. SCEN physicians receive a standard financial compensation from the patient's health insurance company after having written a consultation report. No such compensation is provided for the LEIF physicians. An important difference between both organisations relates to their financial support: SCEN receives €1.000.000 annually from the Dutch government, whereas the direct grant for LEIF physicians from the Belgian government was reduced from 20.000€ in 2003 to 10.000€ in 2007 and ceased in 2008. The organisation does receive some financial support fore.g.publishing the LEIF magazine, a practical guide on end-of-life decisions for the broad public [22].

Discussion

Our study is the first to describe how consultation services in cases of a euthanasia request have been established in the Netherlands and Belgium. In both countries, these consultation services are delivered by specially trained physicians who can be consulted in cases of a request for euthanasia and who offer support and information about the subject. The context in which the two organisations were founded, as well as the way they are organised and regulated, is different in each country: by providing information on all end-of-life care matters the Belgian Life End Information Forum seems to have a broader consultation role than the Dutch Support and Consultation in Euthanasia.
A methodological limitation of this study is that the description of both organisations is based on documents and therefore reflects the theoretical situation but not necessarily the situation in real terms.

One important difference between the consultation organisations in Belgium and the Netherlands is that the Belgian LEIF has a broader focus: its physicians can be consulted not only in cases of euthanasia requests but for all end-of-life issues. The context in which the legislation was developed in Belgium may account for this; in Belgium there was much more controversy than in the Netherlands and the legislature (government) wanted to put the focus on a wider range of options at the end of life. This may explain why a law optimizing the accessibility of palliative care and a law on patient rights emphasizing the right of the patient to choose the care they receive, were passed almost simultaneously with the euthanasia law [30] [31]. In this context the initiators of LEIF, who have a broad background in palliative care, aimed to create a health provision not linked solely to euthanasia. The emphasis on palliative care is not so pronounced with SCEN, although SCEN physicians must consider other palliative options when doing a consultation. As the line between euthanasia and other end-of-life decisions is not always clear to attending physicians and their patients, it can be beneficial to have a service which provides consultation not only in the context of euthanasia but also concerning all medical aspects of the end of life. On the other hand, this requires consultants to have a wider area of expertise.

Another difference between the Dutch SCEN and the Belgian LEIF is that SCEN is more highly-regulated. A historical explanation for this can be found in differences in the development of the euthanasia laws and the fact that, as opposed to Belgium, euthanasia had been tolerated in the Netherlands long before the law was enacted. SCEN also has a longer history than LEIF. Another reason may be that the Royal Dutch Medical Society, which organises SCEN, is controlled and strongly supported financially by the Dutch government, whereas LEIF has no controlling body and little funding. Also a general cultural inclination to formalize practices in the Netherlands may explain why SCEN is more regulated [32].
The heavier regulation of SCEN may provide more of a guarantee that its consultations take place according to best-practice criteria. The more informal contact procedures of LEIF (eg that the attending physician may make direct contact with those in the network) could on the other hand have the advantage of making the service more approachable. If implemented in other countries, such a provision is probably best designed to fit in with the prevailing cultural characteristics.

Several similarities between SCEN and LEIF can be noted. Both organisations were founded to improve (the practice of) consultation in euthanasia requests by specifically training physicians for that purpose. These physicians also support and inform their colleagues on euthanasia. The amount of training time and the guidelines for consultation that are thought during this training are similar in both countries. Furthermore, both associations organise additional meetings to discuss concrete cases. SCEN as well as LEIF have a controlling board consisting of physicians, experts and academics to continuously evaluate the organisations' functioning.

Both The Netherlands and Belgium have been careful to set in place firm and substantial procedural due care requirements in order to safeguard good practice and it can be assumed that other countries intending to legalize euthanasia would do the same. However, the practical implications of legalization are not always covered by legislation. For instance, once euthanasia is legalized, what should a physician do when confronted with a request for euthanasia, and whom should they consult? The creation of specialized service for a priori consultation in euthanasia cases can play an important role. It helps physicians to relatively easily consult a competent second physician when they are confronted with a euthanasia request. Such a service may also guarantee more compliance with the due care requirements and hence function as an additional control mechanism. Research has already demonstrated such services to be of great importance to the careful performance of euthanasia [14]. For instance, the criteria for good consultation (e.g. independence from patient and attending physician, seeing the patient, writing a report) were more often met in consultations with SCEN physicians than with other physicians, and a strong relationship was found between a consultation with SCEN and notification of euthanasia [33]. It is important, however, that the physicians who are part of such services are fully trained to be able to judge the conditions for euthanasia and guarantee a good practice. Both SCEN and LEIF put emphasis on knowledge of the law and of palliative care, and on communication with the patient and the attending physician.
The evaluation report of the euthanasia law showed that SCEN physicians had been involved in 89% of all notified euthanasia cases in the Netherlands [33]. The notification reports in Belgium and a first assessment of LEIF activities [34] indicate that LEIF physicians have acted as a second physician in 54% of reported euthanasia cases in Flanders [35]. This shows the important involvement of this service in euthanasia. SCEN and LEIF can be an example for countries that have recently legalized euthanasia, like Luxembourg, or are discussing legalization. These countries can learn from the similarities and differences between both initiatives in organising such a service according to their law, health system and culture.

Conclusions

In conclusion, this study shows that similar consultation services were developed in the Netherlands (SCEN) and in Belgium (LEIF) to provide an accessible, independent and qualified second physician in cases of a request for euthanasia. Though some important differences exist between the initiatives relating to the history and culture of the two countries, they are both intended to safeguard the practice of euthanasia. As both SCEN and LEIF play an important role in the performance of euthanasia in their respective countries, it is possible to conclude that, in countries where legislation on physician-assisted death is being considered, the development of such a service is warranted, parallel to or even incorporated into the relevant laws.

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Chapter 5

Implementation of a service for consultation and information in euthanasia requests in Belgium

Van Wesemael Y, Cohen J, Bilsen J, Smets T, Onwuteaka-Philipsen B, Distelmans W, Deliens L. Implementation of a service for consultation and information in euthanasia requests in Belgium. Submitted.

Abstract

Aim

To study the implementation of LEIF, the consultation service which provides access to specially-trained physicians to act as the legally-required second physician in requests for euthanasia in Flanders and Brussels, Belgium, the use of which has been to shown to be beneficial to the careful practice of euthanasia

Method

A representative sample of 3,006 Belgian physicians from the area where LEIF is active received a questionnaire investigating their attitude and practice regarding euthanasia, asking about their knowledge of LEIF, their attitude towards the service, their use of the service and their intentions regarding its future use.

Findings

Three aspects of implementation were successful: 78% of physicians knew about the existence of the organization, 90% felt supported by the idea of being able to consult a LEIF physician and 90% intended to use LEIF in the future. However, only 35% of those who had received a euthanasia request since LEIF became active had made use of LEIF. Awareness, use and intended use of LEIF were lower among specific groups of physicians (e.g. specialists). Positive attitudes towards consultation and training were positively associated with future use of LEIF.

Conclusion

Implementation can be considered successful but LEIF should continue promoting its services as widely as possible, with specific attention paid to specialists.

Keywords: euthanasia, health service, consultation

Introduction

In Belgium, consultation with an independent physician is one of the due care requirements for the attending physician considering a request for euthanasia,i.e.the ending of life by the physician at the patient's explicit request (1). This second physician must be independent from both the attending physician and the patient, must have read the patient's file, must examine the patient and must be satisfied that they are experiencing unbearable physical or psychological suffering due to a serious incurable disease. Similar requirements apply in the Netherlands and Luxembourg, the only other countries where euthanasia is legal (2; 3). In the year following the enactment of the Belgian euthanasia law in September 2002, a special non-governmental service called the Life End Information Forum (LEIF) was created by individuals with experience in palliative care together with the association Right to Die With Dignity. The main aim of this initiative was to inform physicians about end-of-life care and specifically euthanasia, since many did not have much knowledge or experience of this matter (4; 5) and to provide trained people able to act as mandatory second physicians in euthanasia requests, since such physicians would probably be hard to find given that cases of euthanasia are rare and require specific procedure (6). The organization of LEIF was partly based on an existing Dutch service called Support and Consultation for Euthanasia in the Netherlands (SCEN), which had been operating since 1997 (7) (8). LEIF provides training for physicians in the skills and knowledge necessary to act as independent consultants in euthanasia requests. Attending physicians who receive a euthanasia request and who want to consult with an independent physician can call a central telephone number and a LEIF physician is then assigned to them, or they can contact a LEIF physician directly. Previous research has already demonstrated that consulting a LEIF physician contributes to the careful practice of euthanasia. For instance, involving a LEIF physician was a better guarantee of the independence of the second physician from the attending physician and the patient than was involving a non-LEIF physician (9). Beside this, LEIF physicians can also act as informal consultants for colleagues who need advice on end-of-life decisions other than euthanasia (10).
Since its foundation, the Life End Information Forum has been promoting its services through various channels including a website and the weekly periodical De Huisarts sent to all GPs. Moreover, their information brochure has been distributed widely to pharmacists, public libraries and communities. Until now, however, it has not been known to what extent the service has been successfully implemented in the region where it is active, namely Flanders and Brussels. In this study, we assess the four steps which, based on the innovation theory of Rogers, are considered to be necessary for the implementation of such a service: awareness, attitude, past use and future use (11). Prevalence of these aspects should be as high as possible for implementation to be successful. Our research questions are: how many physicians in Flanders and Brussels know about the existence of LEIF (awareness)? How supported do they feel about being able to call a LEIF physician for consultation in cases of euthanasia requests (attitude)? How many of them have already made use of LEIF in the past as part of a euthanasia request (use)? How many would use LEIF in the future in case of a euthanasia request (future use)? Are physician characteristics (and if so, which characteristics) associated with awareness of LEIF, with feeling supported by the idea that there is a service such as LEIF for consultation, with having used LEIF in the past or with having the intention of using LEIF in the future?

Study design

In March 2009, a mail questionnaire was sent to a sample of 3,006 registered medical practitioners who worked in Belgium, had graduated in their specialty at least 12 months beforehand and were likely to be involved in the care of the dying. Specialties for which little or no experience in care for the dying could be expected were excluded. The sample comprised general practitioners, anesthesiologists, gynecologists, internists, neurologists, pulmonologists, gastroenterologists, psychiatrists and neuro-psychiatrists, cardiologists, radiotherapists and surgeons; it was stratified for province and specialty and represents a sampling fraction of 9.2%. Due to a privacy law making official registers from the National Institute for Health and Disability Insurance (NIHDI) unavailable to researchers, the random proportional sample was drawn from a commercial register based on the NIHDI register and updated weekly.

Each questionnaire had a unique serial number and the recipients were requested in a covering letter to send it to an independent lawyer to guarantee complete anonymity while allowing for the sending of up to three reminders (12). The anonymity procedure and study protocol were approved by the Ethical Review Board of the University Hospital of the Vrije Universiteit Brussel.

To assess non-response bias non-responders were sent a one page form asking their reasons for not participating and requesting them to fill in two key questions from the original questionnaire, one about their attitude towards euthanasia and the other about whether they had ever received a euthanasia request (13).

Questionnaire

In the pre-structured, eight-page questionnaire containing mainly closed-end questions, euthanasia was defined according to its legal definition in Belgium as 'the intentional ending of the patient's life at his/her explicit request by the physician'. The questions asked about LEIF were: were you aware of the existence of LEIF before receiving this questionnaire? Have you ever consulted with a LEIF physician in the case of a euthanasia request by one of your patients? Where applicable, would you consult a LEIF physician in future in the case of a euthanasia request by one of your patients? To what extent do you feel supported by the idea that you can appeal to a LEIF physician for the mandatory consultation with a second physician in the case of a euthanasia request? To what extent do you feel supported by the idea that you can make an appeal to a LEIF physician for information and advice on questions regarding end-of-life care?

Statistical analysis

For all analyses we selected only Dutch-speaking physicians from Flanders and Brussels because LEIF offers its services and training only in Dutch. Fisher exact tests were used to compare between those who did and those who did not know about LEIF, make use of LEIF, intend to use LEIF and feel supported by LEIF. P-values of less than 0.05 were considered statistically significant. Backward stepwise logistic regressions were performed to identify the physician characteristics associated with awareness of LEIF, past use of LEIF, intention to use LEIF in future and feeling supported by the idea of being able to consult a LEIF physician in the case of a euthanasia request. Odds ratios (ORs) and 95% confidence intervals (CIs) are presented. The analyses were performed using SPSS 19.0 and StatXact 6.

Response

Of the 3,006 physicians sent a questionnaire, 222 were unreachable, deceased or no longer in practice. From the non-response survey another 57 were identified as no longer practicing or not having received the questionnaire. There were 2,726 eligible respondents, from whom 914 questionnaires were returned, bringing the overall response rate to 34%. Significant differences between the responders to the survey and the responders to the non-response survey were found for attitude towards euthanasia, although both groups strongly agreed with the statement concerning attitude towards euthanasia. No differences between these groups were found concerning ever having received a request (13).

Physician characteristics and attitudes

Five hundred and twenty-six physicians in the obtained sample of 914 were Dutch-speaking from Flanders and Brussels. Of these, 67.1% were GPs, the majority (73.6%) were between 36 and 60 years old and 68.4% considered themselves religious (Table 1). A little over half (55.4%) had followed a training programme in palliative care or were members of a palliative care team and 67% had cared for between one and ten terminally ill patients during the last year.
Almost 93% agreed that administering life-ending drugs at the explicit request of the patient is acceptable in terminally ill patients with extreme uncontrollable pain or other uncontrollable suffering. Eighty-six per cent agreed that consulting a second physician is useful in every request and 87.6% thought consultation contributes to careful practice at the end of life. A little over half (53.1%) agreed that, to be able to give advice as the second physician in a euthanasia request, one has to have followed a special training programme.

Table 1: characteristics of the studied physicians

Physician characteristics and attitudes	N (%)*
All physicians	526
Speciality	
General practitioner	344 (67.1)
Specialist	169 (32.9)
Age	
Younger than 36	68 (13.2)
36-50 years	188 (36.5)
51-60 years	191 (37.1)
Older than 60	68 (13.2)
Number of terminal patients cared for in the past year	
0 patients	97 (20.6)
1 to 10 patients	315 (67.0)
more than 10 patients	58 (12.3)
Religion	
Not religious	164 (31.6)
Religious	355 (68.4)
Training in palliative care or member of palliative team	
Yes	289 (55.4)
No	233 (44.6)
Attitude towards euthanasia	
terminally ill patients with extreme uncontrollable pain or other uncontrollable suffering	
Agree to totally agree	481 (92.7)
Neutral	14 (2.7)
Disagree to totally disagree	24 (4.6)
Attitudes towards consultation in euthanasia requests	
Consulting a second physician is useful in every request	
Agree to totally agree	444 (85.9)
Neutral	41 (7.9)
Disagree to totally disagree	32 (6.2)
To be able to give an advice as second physician in euthanasia requests, you have to have followed a special training	
Agree to totally agree	274 (53.1)
Neutral	111 (21.1)
Disagree to totally disagree	131 (24.9)
Consulting a second physician contributes to the due care handling by physicians at the end of life	
Agree to totally agree	452 (87.6)
Neutral	41 (7.9)
Disagree to totally disagree	23 (4.5)

* 4 to 56 (number of terminally ill patients cared for) missing cases

Implementation of LEIF

Awareness
We found that 78.2% (N=406) were aware of the existence of the organization (Table 2). General practitioners (GPs), significantly more often than specialists, knew of the existence of LEIF, as did physicians who had received training in and had experience with palliative care compared with those who had not. Physicians who had cared for between one and ten terminally ill patients in the last year also more often knew of the existence of LEIF than those who had cared for more than ten patients or for none. Physicians with a positive attitude towards the usefulness of consulting more often knew of LEIF than those with a negative attitude.

Attitude
Almost 90% felt supported by the idea of being able to consult a LEIF physician, 59% (N=303) to a large extent and 30.3% (N=156) somewhat (not in table). Those younger than 36 years indicated significantly more often than did older physicians that they felt supported by the idea of LEIF (Table 2), while those who had cared for more than ten terminally ill patients in the past year felt less supported by the idea of LEIF. Physicians who had a positive attitude towards euthanasia and towards consultation more often felt supported (Table 2).

Ninety-two percent of the responding physicians felt supported by the idea of being able to appeal to a LEIF physician for information and advice on end-of-life care. Those who had cared for more than ten terminally ill patients in the last year (81.0%) less often felt supported by the idea of LEIF for information compared with those who had cared for between one and ten (92.3%) or for none (97.9%). Physicians with a positive attitude towards euthanasia also felt more supported by the idea of LEIF for information, compared with those with a negative attitude (93. 9% vs 70.8%). All the respondents younger than 36 felt supported by the idea of LEIF for information, compared with around 88% of those older than 51. Physicians with a positive attitude towards consultation also felt more supported than those with a negative attitude (not in table).

Use
One fifth (N=102) of all respondents had already made use of a LEIF physician in the past (Table 2) of whom 71.3% (N=72) had done so once, 12.9% (N=13) twice and 14.9% (N=15) three times or more (not in table). The use of LEIF increased to 35.4% for physicians who had received a euthanasia request since LEIF was active. GPs had consulted significantly more often with a LEIF physician in the case of a euthanasia request than had specialists. Physicians with training in palliative care or those who were members of a palliative team and those older than 60 had consulted a LEIF physician more often than had those without training and those younger than 60. Those who had cared for between one and ten terminally ill patients in the past year had made use of a LEIF physician in consultation notably more often than those with more than ten terminally ill patients or with none at all.

Future use
Of the responding physicians, 89.7% (N=455) would consult a LEIF physician in future (Table 2). Physicians younger than 36 years compared with the older physicians, and GPs compared with specialists, indicated their intention of consulting a LEIF physician significantly more often. Those who had cared for more than ten terminally ill patients during the past year were less inclined to consult with a LEIF physician in the future. Physicians with a positive attitude towards euthanasia and towards consultation were also more inclined to consult a LEIF physician in the future.

Factors associated with awareness, attitude, use and future use of LEIF

Factors positively associated with knowing LEIF were being a GP (OR 3.13), having followed training in palliative care or being member of a palliative team (OR 3.54) and having a positive attitude towards the usefulness of consultation (OR 3.54).

Factors positively associated with feeling supported by the idea of being able to consult a LEIF physician were having a positive attitude towards following special training on consultation (OR 5.61) and having a positive attitude towards the usefulness of consultation in a euthanasia request (OR 7.30). Having cared for more than ten terminally ill patients in the past year was negatively associated with this (OR 0.13).

Being a GP was positively associated to having used LEIF in the past (3.32).

Factors positively associated with future use were being a GP (2.56), having a positive attitude towards the need for special training in consultation (OR 2.86), having a positive attitude towards euthanasia (OR 4.83) and having a positive attitude towards the usefulness of consultation (OR 8.82). Having consulted with a LEIF physician in the past was a highly predictive factor for future use (OR 25.03, CI 2.82-221.78, not in table). Having cared for more than ten terminally ill patients in the past year was negatively associated with this (OR 0.25).

Table 2: factors associated with awareness of LEIF, feeling supported by the idea of LEIF, use of LEIF and intention to use LEIF

Physician characteristics	Knows of existence of LEIF		Feels supported by idea of LEIF for consultation		Has already used LEIF		Intends to use LEIF in future	
	Yes (%)*	OR (95% CI) †	Yes (%) ‡	OR (95% CI)	Yes (%)	OR (95% CI)	Yes (%)	OR (95% CI)
All physicians	78.2		89.1	/	20.1	/	89.7	/
Speciality								
General practitioner	**87.4**	**3.13 (1.87-5.24)**	90.3	/	**26.3**	**3.32 (1.65-6.68)**	**92.8**	**2.56 (1.09-6.03)**
Specialist	60.6		87.0	/	7.5	1.00	84.4	1.00
Age								
Younger than 36	75.0	/	**98.5**	/	12.1	/	**97.0**	/
36-50 years	73.3	/	90.8	/	18.9	/	88.5	/
51-60 years	82.2	/	85.8	/	19.8	/	88.8	/
Older than 60	82.1	/	85.1	/	**30.2**	/	89.2	/
Number of terminal patients cared for in the past year								
0 patients	**64.2**	/	94.7	1.00	**7.7**	/	92.4	1.00
1 to 10 patients	**82.5**	/	91.1	0.657 (0.16-2.08)	**24.9**	/	92.2	0.68 (0.23-2.01)
more than 10 patients	75.9	/	**71.9**	**0.13 (0.03-0.54)**	15.8	/	**76.4**	**0.25 (0.08-0.83)**
Religion								
Not religious	77.4	/	88.4	/	22.0	/	87.4	/
Religious	78.8	/	89.7	/	19.4	/	91.0	/
Training in palliative care or member of palliative team								
Yes	**90.3**	**3.54 (2.07-6.06)**	88.2	/	**27.2**	/	90.4	/
No	63.2		90.4	/	11.2	/	89.3	/
Attitude towards euthanasia								
Administering life-ending drugs at the explicit request of the patient is acceptable with terminally ill patients wit extreme uncontrollable								

pain or other uncontrollable suffering								
Agree to totally agree	77.2	/	**91.4**	/	20.3	/	**91.8**	**4.83 (1.30-17.87)**
Neutral	92.9	/	**69.2**	/	15.4	/	**71.4**	0.46 (0.08-2.73)
Disagree to totally disagree	87.5	/	**62.5**	/	16.7	/	**66.7**	1.00
Attitude towards consultation in euthanasia requests								
Consulting a second physician is in every request useful								
Agree to totally agree	**80.0**	**3.54 (1.38-9.09)**	**92.5**	/	20.1	/	**93.1**	**8.22 (2.73-24.82)**
Neutral	75.6	2.42 (0.71-8.28)	**70.7**	/	27.5	/	**74.4**	1.45 (0.38-5.46)
Disagree to totally disagree	**59.4**	1.00	**65.6**	/	12.5	/	**63.3**	1.00
To be able to give an advice as second physician in euthanasia requests, you have to have followed a special training								
Agree to totally agree	80.3	/	**96.3**	**5.61 (2.30-13.65)**	17.5	/	**94.1**	**2.68 (1.17-6.15)**
Neutral	73.9	/	87.3	**2.75 (1.06-7.09)**	18.5	/	**92.6**	**3.57 (1.16-10.99)**
Disagree to totally disagree	77.9	/	**75.6**	1.00	**27.3**	/	**78.6**	1.00
Consulting a second physician contributes to the careful handling by physicians at the end of life								
Agree to totally agree	79.2	/	**93.8**	**7.30 (1.99-26.71)**	21.1	/	**92.8**	/
Neutral	78.0	/	**63.4**	0.70 (0.16-3.08)	12.5	/	**73.7**	/
Disagree to totally disagree	60.9	/	**43.5**	1.00	17.4	/	**60.9**	/

* Significance tested with StatXact, Fisher exact test for statistically significant differences between categories vs all other categories within the variable.
† All variables significant in the bivariate analysis were added in a stepwise backward multiple regression.
‡ 'Yes' comprises the answer categories 'To a large extent' and 'Somewhat' whereas 'No' comprises the answer categories 'Hardly' and 'Not'.

Discussion

This study assessed the implementation of the Life End Information Forum (LEIF) after five years of existence in terms of awareness, use, future use and the attitudes of Dutch-speaking Flemish and Brussels physicians likely to be involved in end-of-life care (11). Three aspects of implementation according to the innovation theory of Rogers were fulfilled: over three quarter of responding physicians knew of the existence of LEIF, almost 90% would consult with a LEIF physician in the future in the case of a euthanasia request and 90% felt supported by the idea of being able to consult one in such cases. However, the fourth aspect i.e. past use had been fulfilled by only 35% of those responding physicians who had received a euthanasia request since LEIF became active.

Despite the rigorous sampling and mailing procedure and the comprehensive testing of the questionnaire the response percentage is low, making it difficult to generalize the results to all Dutch-speaking physicians with possible experience in end-of-life care in Flanders and Brussels. However, analysis of the non-response survey does not show a significant difference between the respondents to that and to the survey itself ever having received a euthanasia request. But since we found that respondents to the survey have a slightly more positive attitude to euthanasia than do the respondents to the non-response survey, they might also be more positive towards consultation. This could mean that the actual intention of future use of LEIF may be lower than is reflected by our results, since a positive attitude toward consultation is a predicting factor for future use.

With over three quarter of those physicians who are potentially involved in end-of-life care and who work in the region covered by LEIF knowing of its existence, and almost 90% indicating they would consult a LEIF physician in future euthanasia requests, the implementation of LEIF can be considered to be relatively successful. The figure of 35% of those having received a euthanasia request since the founding LEIF and who had actually used the LEIF service, however, can be considered on the low side.
When comparing our results with those from the Netherlands, the only other country having such a consultation service (SCEN), we found that implementation in the Netherlands was more successful. Nearly all Dutch GPs knew about the existence of SCEN a year and a half after the project had started and 63% of the GPs who had received a euthanasia request in the past year had consulted a SCEN physician (14). A possible reason that may partly explain this difference is that only GPs participated in the Dutch study. In our study, GPs also knew more often than specialists about LEIF and had consulted more often with LEIF. The more successful implementation in the Netherlands could also be attributed to the way SCEN was founded and promoted, as it was the Royal Dutch Medical Association and the Association of General Practitioners who initiated the project (7) (15). The fact that SCEN physicians receive standard financial compensation from the patient's insurance company after writing a consultation report means their work is officially recognized, unlike that of the LEIF physicians who receive no such standard compensation. Also, a quarter of the Dutch physicians are of the opinion that a consultation with a SCEN consultant should be mandatory (16). A stronger inclination to formalize practices, due to cultural differences, may also explain why the implementation of SCEN has been more successful than that of LEIF (17). We also found important differences concerning attitudes towards consultation: in Flanders, only a little over half of respondents agreed that a special training was necessary to be able to advise as a second physician whereas this was 87% in the Netherlands. With almost 40 years' history of the practice of euthanasia and an incorporated consultation procedure existing for almost 25 years, as a result of the Dutch policy of tolerance towards euthanasia, Dutch physicians have not only developed a

positive attitude toward euthanasia but appear to attach more importance to the procedural requirements than do Belgian physicians (18) (19) (20).

The awareness, use and intended use of LEIF appear to be lower among specific groups of physicians. Specialists were, for instance, less often aware of the existence of LEIF, had consulted less often with a LEIF physician in the past and were less likely to do so in the future than were GPs. While specialists probably find it easier to consult a colleague from within their own hospital, it may be important to increase their awareness and use of LEIF since its use can contribute to guaranteeing the legal requirement for the second physician to be independent (9).
Our results indicate that many physicians towards the end of their careers (i.e. older than 60) particularly, who might be the least familiar with the legal procedures, had already used a LEIF physician, and many of those at the start of their career (i.e. younger than 36) who might have less experience in euthanasia practice, intend to use LEIF in the future. The latter group also felt more supported by the idea of being able to appeal to a LEIF physician for information and advice. LEIF could focus on supporting these physicians in particular,e.g.by providing brochures to young graduates, and make sure they find their way to the organization whenever they need a second physician or advice. On the other hand, the physicians who had cared for more than ten patients in the past year less often intended to use LEIF or felt supported by the idea of LEIF. Such physicians, mostly specialists, probably have their own informal network of colleagues to whom they turn for mandatory consultation but this carries the risk that the independence criteria may not be fulfilled and it might therefore be beneficial for them also to consult a LEIF physician.

We found a large discrepancy between the past use of LEIF (35%) and the intention of future use (90%) for physicians who have already dealt with a euthanasia request. This might indicate that physicians were not aware in the past or are still not aware of exactly which services LEIF offers. We checked whether those who did not know about LEIF before filling out the questionnaire might be influenced by the process and hence be more inclined to use LEIF in the future than would those already aware of LEIF but this was not the case. Although the respondents to our survey have a positive attitude towards consultation and towards LEIF which, we found, is a predicting factor of future use, our results show that past use plays an even more important role in future use. Hence it might be that in practice, not all physicians who indicated the intention of using LEIF will do so, suggesting that this aspect of implementation should be taken into consideration and should be further explored. Also, between the founding of LEIF and our study, LEIF may have become more effective in publicising itself.

Conclusion and recommendations
After five years of existence, LEIF has been successfully implemented in three areas: awareness, future use and attitude. Past use of LEIF among Dutch-speaking Flemish and Brussels physicians with possible experience in end-of-life care is low. In order to encourage physicians to make use of the LEIF service for consultation, LEIF should continue promoting its services as widely as possible. Promoting LEIF in hospitals to specialists who are used to consulting with colleagues from within the hospital would also be helpful in order to guarantee the legal requirement of independence. Support from the government,e.g.in the form of reimbursement for the consultation, would formalize LEIF as a consultation service and would therefore also increase the use of the service.

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Chapter 6

Role and Involvement of Life End Information Forum Physicians in Euthanasia and Other End-of-Life Care Decisions in Flanders, Belgium

Van Wesemael, Y; Cohen, J; Onwuteaka-Philipsen, BD; Bilsen, J; Distelmans, W; Deliens, L. Role and Involvement of Life End Information Forum Physicians in Euthanasia and Other End-of-Life Care Decisions in Flanders, Belgium. Health Services Research 2009, 44:6.

Abstract

Objective

To describe role and involvement of Life End Information Forum (LEIF) physicians in end-of-life care decisions and euthanasia in Flanders.

Study design

All 132 LEIF-physicians in Belgium received a questionnaire inquiring about their activities in the past year, and their end-of-life care training and experience.

Principal findings

Response rate was 75%. Most respondents followed substantive training in end-of-life care. In one year, LEIF-physicians were contacted 612 times for consultations in end-of-life decisions, of which 355 concerned euthanasia requests eventually resulting in 221 euthanasia cases. LEIF-physicians also gave information about various end-of-life issues (including palliative care) to patients and colleagues.

Conclusions

LEIF-physicians provide a forum for information and advice for physicians and patients. A similar health service providing support to physicians for all end-of-life decisions could also be beneficial for countries without a euthanasia law.

Key Words. Consultation, euthanasia, end-of-life decisions

Introduction

In 2002, both Belgium and the Netherlands enacted a law on euthanasia,i.e.the deliberate ending of a patient's life by a physician at the patient's request (1; 2). Euthanasia is a medical practice requiring great care. Therefore, the mandatory consultation of an independent physician was incorporated into the Dutch and Belgian laws as one of the procedural criteria of due care. This independent physician has to read the medical file, consult both attending physician and patient and make a written report. In the Netherlands, where a long history of jurisprudence concerning the practice of euthanasia preceded its legalization (3-7), the Royal Dutch Medical Association initiated a nation-wide consultation project for euthanasia in 1999 called 'Support and Consultation for Euthanasia in the Netherlands' (SCEN). Physicians who received a euthanasia request could call a central number and request a formal consultation by an assigned consultant physician.

The Belgian euthanasia law was not preceded by a history of jurisprudence and the legislature did not provide a consultation project like in the Netherlands (8). In 2003, a group of individuals with experience in end-of-life care used SCEN as a model to create a similar initiative for the Flemish speaking community in Belgium (9-11). They founded LEIF (Life End Information Forum) intending not only to help physicians confronted with euthanasia requests in finding a specifically trained, accessible, and independent physician for a formal consultation as required by the euthanasia law, but also to offer a wide information and support forum for both professional caregivers and patients who have questions about the end of life (including palliative care). The law does not compel attending physicians to consult via LEIF, which is to date a voluntary association, originally funded by the government. If they do so, they are not obliged to first contact the LEIF secretariat, which is staffed by the coordinator, a social nurse and a pharmacist. LEIF-physicians are offered five training modules (24 hours in total) on several end-of-life decisions, the practice of euthanasia and related communication and are encouraged to attend biannual 'intervision' groups to discuss and evaluate practices.

In Belgium, the frequency of prior consultation of colleague-physicians in medical end-of-life practices has been studied (12-15), but unlike in the Netherlands (16-19) no studies have looked at the characteristics of the consulting or consulted physician and of the consultation itself or have described and evaluated LEIF. This paper, therefore, aims to describe characteristics of LEIF-physicians and their activities concerning consultation, information and advice in end-of-life decisions during a one-year period, and provide insight into their involvement in euthanasia cases. We will address three research questions: 1) what are the characteristics of LEIF-physicians and what training and experience with end-of-life care do they have? 2) What kind of requests do LEIF-physicians receive, by whom and via which route? 3) What is the actual involvement of LEIF-physicians in euthanasia cases?

Data collection

A descriptive retrospective study was conducted. The LEIF secretariat identified 132 physicians who - at the time of the study (May to September 2008) - had followed at least two modules of the LEIF training and were hence considered to function actively as LEIF-physicians. The LEIF secretariat sent a mail questionnaire with a unique serial number to all LEIF-physicians, requesting them to return it to the researchers, who communicated to the LEIF secretariat which serial numbers had been received, hence enabling the sending of up to three reminders in cases of non-response. The survey was done according to the Total Design Method (Dillman, 1991) (questionnaire kept fairly short, cognitive pretesting, pre-notice letter signed by director of LEIF, individually addressed mailings, prepaid return envelope, three reminders,). The anonymity of the physicians was guaranteed as the researchers removed the serial numbers from the questionnaires, had no access to the database of the LEIF secretariat with the personal details of all LEIF-physicians and the LEIF secretariat had no access to the completed questionnaires. The study received approval from the ethics committee of the University Hospital of the Vrije Universiteit Brussel.

Questionnaire

The questionnaire drew partly on the yearly Dutch registration form of the activities of SCEN physicians (19) and on the questionnaires of the SCEN evaluation study (17). The first part asked about the physician's socio-demographics and end-of-life care experience and training. The second part asked about their activities as LEIF-physicians during the past year regarding: 1) consultation in euthanasia requests; 2) consultation in other end-of-life decisions (including palliative care) such as non-treatment decisions and terminal sedation; and 3) the provision of information to physicians, patients and their family and others. Regarding the consultations in cases of requests for euthanasia, the LEIF-physicians were asked in more detail about their involvement in the decision-making process.

Response

Four physicians were no longer active as LEIF-physicians. Of the remaining 128, 96 (75%) participated in the study. Analyses for non-response bias showed no significant differences for gender, age, province, speciality and number of modules from the LEIF training program followed.

Characteristics LEIF-physician

Almost 65% of the respondents were 50 years or older (not in table). The age group 30-39 years was under-represented compared to all physicians in Flanders and Brussels ($p<0.01$). LEIF-physicians have a proportional distribution over all provinces of Flanders. Of all respondents, 73% are general practitioners (GPs), significantly more than in the total population of physicians in the regions studied ($p<0.01$).

End-of-life care training and experience

About 73% of respondents followed some education in end-of-life care additional to the LEIF training (Table 1). They attended on average four seminars (stdev=11.5) and nine entire study days (stdev=45.4) on end-of-life care (not in table). Almost 41% followed the 30 hour post-graduate interuniversity training in palliative care. A quarter are part of a hospital or home care multidisciplinary palliative care team (Table 1).
Over 30% cared for 10 or more terminal patients during the past year. This differed per speciality: GPs had care of, on average, six patients and specialists of 72 patients. About 5% were not part of a palliative team, had not attended any kind of training in end-of-life care besides the LEIF courses and had not cared for any terminally ill patients in the last year.

Table 1: end-of-life care training and experience of LEIF-physicians (N=96)

	N LEIF-physicians (%)
Additional training in end-of-life care	69 (73.4)
Post graduate studies in palliative care*	39 (40.6)
Study days in end-of-life care	48 (50.0)
Seminars in end-of-life care	52 (54.2)
Training weekends on end-of-life care and bereavement …	17 (17.7)
End-of-life care training during internship	8 (8.3)
LEIF training: number of modules followed†	
2 modules	12 (12.5)
3 modules	16 (16.7)
4 modules	26 (27.1)
5 modules	42 (43.8)
Member of palliative team‡	25 (26.0)
Number of incurably ill patients cared for at their end of life in the past year	
< 5 patients	42 (43.8)
5-9 patients	21 (21.9)
10-19 patients	17 (17.7)
≥ 20 patients	13 (13.5)

The numbers mentioned in table 1 are N physicians (%)
*the post graduate studies in palliative care are organized in cooperation with several Flemish universities and the Federation of Palliative Care Flanders. This course of 30 hours training in 1 year is for physicians
† data were provided by the LEIF secretariat. The maximum number of modules in the LEIF training is 5. We chose to select the physicians who followed at least 2 modules for this study because this is the minimum being requested for practicing as LEIF-physician.
‡ a palliative team in Belgium is a multidisciplinary team consisting of one or more physicians, nurses, psychologist, and other paramedics that is active in a hospital setting or at home.

Requests for consultation and information

Nearly three quarters of all responding LEIF-physicians had been contacted for consultation as a second physician in a euthanasia request in the past year; on average almost four times per LEIF-physician. The majority (63.5%) were contacted directly by the attending physician (Table 2). Fewer were contacted by the LEIF secretariat (35.4%), by the patient (17.7%), or via another route (eg family of patient, psychologist: 5.2%). Almost 27% had not been contacted for consultation in euthanasia requests during the past year. Having been contacted for consultation was not related to gender, age, region, speciality and number of LEIF training

modules attended, but physicians with additional education in end-of-life care were contacted more often than those without (p=0.03) (not in table).

Table 2: type and frequency of initial consultation requests to LEIF-physicians (N=96) during a one year period

	Number of LEIF-physicians who were contacted (%)*	Average per LEIF-physician (stdev) †
Consultation		
For consultation in euthanasia requests‡	70 (72.9)	3.70 (4.93)
contacted by LEIF secretariat	34 (35.4)	0.94 (1.71)
contacted directly by attending physician	61 (63.5)	2.28 (3.63)
contacted directly by patient	17 (17.7)	0.28 (0.75)
contacted in other way	5 (5.2)	0.07 (0.33)
For consultation in other ELDs	28 (29.2)	2.12 (5.06)
non treatment decision	16 (17.4)	1.03 (3.05)
continuous sedation until death	15 (17.4)	0.54 (1.81)
alleviation of pain and symptoms	24 (26.1)	1.12 (3.13)
life ending act where patient consent is no longer possible	5 (5.4)	0.10 (0.49)
Information about**		
legal procedure euthanasia	78 (90.7)	12.51 (2.18)
by physicians	62 (70.1)	3.72 (6.32)
by patients	59 (68.6)	7.33 (13.9)
by others ††	18 (20.9)	1.56 (3.95)
living will arrangement	75 (87.2)	12.21 (1.85)
by physicians	39 (45.3)	2.93 (6.99)
by patients	63 (73.3)	7.63 (12.38)
by others††	19 (22.1)	1.65 (4.43)
palliative care	55 (64)	10.79 (1.87)
by physicians	28 (32.6)	3.41 (11.98)
by patients	47 (54.7)	6.20 (9.96)
by others††	13 (15.1)	1.19 (3.36)
practical performance of euthanasia	54 (62.8)	4.71 (0.87)
by physicians	46 (53.5)	2.62 (6.02)
by patients	30 (34.9)	1.57 (3.59)

by others[††]	6 (7.0)	0.52 (2.47)
the LEIF association	50 (58.1)	6.64 (1.18)
by physicians	40 (46.5)	2.87 (6.59)
by patients	31 (36.0)	2.85 (6.17)
by others[††]	10 (11.6)	0.92 (2.70)
other medical end-of-life decisions besides euthanasia	47 (54.7)	6.41 (1.16)
by physicians	25 (29.1)	1.79 (4.22)
by patients	36 (41.9)	3.79 (8.14)
by others[††]	9 (10.5)	0.83 (2.89)

* percentage of physicians are calculated for total responding in each category
† average number of demands by physician for all responding physicians (standard deviation of average number)
‡ multiple responses possible
** 10 missing observations
[††] others can be anyone (except colleague physicians, patients and patients' family) who asks the LEIF-physician for information e.g. the physician's entourage, care workers, etc.

Almost 30% of LEIF-physicians were contacted for consultation in end-of-life decisions other than euthanasia, on average twice per LEIF-physician per year (Table 2). They reported 103 consultations for possibly life-shortening alleviation of symptoms and pain, 95 within the context of a non-treatment decision, 50 for continuous deep sedation until death and nine for life-ending acts with no explicit request from the patient (not in table).

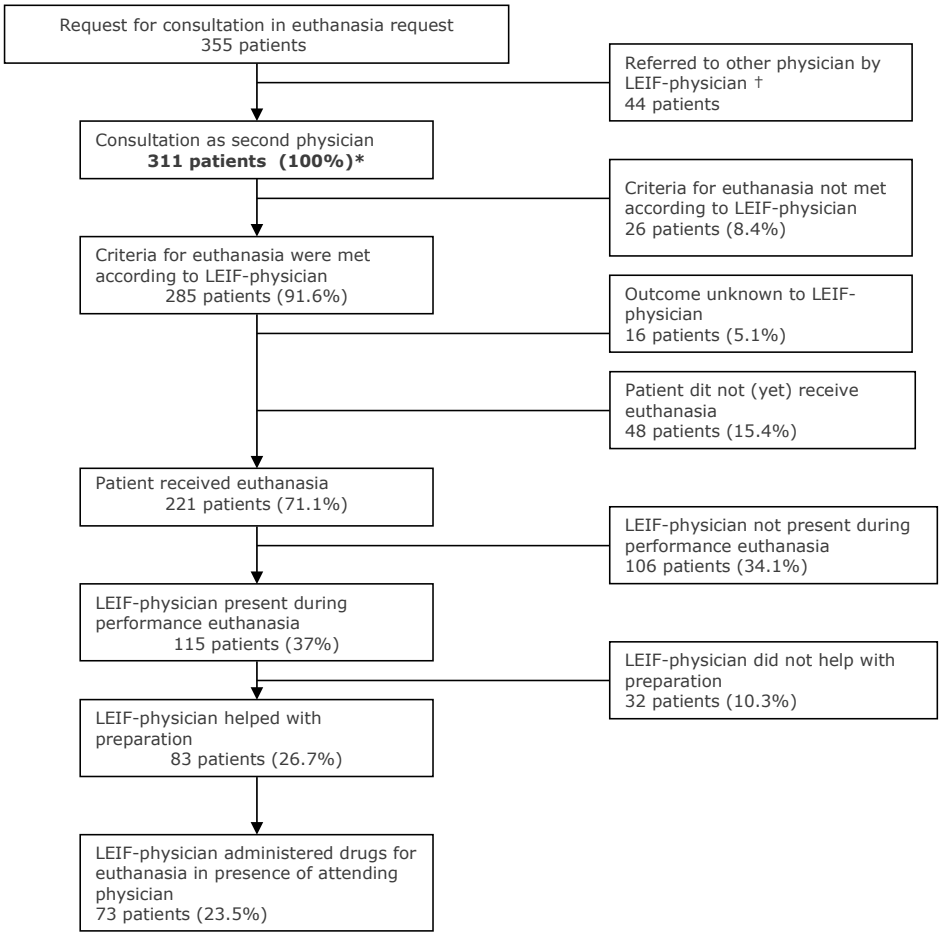
About 86% were contacted to provide information. In one year they received 2518 requests for information by patients, mostly about living wills (n=656), the legal procedure of euthanasia (n=623) or palliative care (n=533), and 1491 requests by physicians, of which 37% (n=545) were about the legal procedure or practical performance of euthanasia (not in table).

Involvement of LEIF-physicians in euthanasia cases

The responding LEIF-physicians were asked to consult as a second physician in 355 cases of euthanasia requests (Figure 1). Of these, 311 resulted in an actual consultation with the LEIF-physician. In 285 cases (91.6% of the consultations) the LEIF-physician evaluated all due care criteria to have been met and 221 (71.1%) resulted in euthanasia. LEIF-physicians were present at the time of euthanasia in 115 cases (37%) and helped with the preparation in 83 (26.7%). In 73 (23.5%) cases, they administered the drugs themselves in the presence of the attending physician. In the open question at the end of the questionnaire, some physicians reported reasons for performing the euthanasia themselves e.g. because the attending physician did not want to do it for personal or medico-technical reasons.

At the level of physicians, 69.8% of the LEIF-physicians did at least one consultation as a second or third physician in a euthanasia request during the past 12 months. One third had been present at least once at the time of euthanasia, 38.5% had helped at least once with the preparation of the act and 27.1% had administered the drugs for euthanasia at least once.

Figure 1: Involvement of LEIF-physicians in euthanasia cases



*The numbers mentioned in figure 1 are N patients and percentages from total consultations N=311
† Reasons for referring to another physician could be that the LEIF-physician was not available at time of contact, that the LEIF-physician considered him/herself not independent from the attending physician, etc.

This study describes the characteristics and activities of the physicians of the Life End Information Forum (LEIF), which was initiated as a specialized supporting health service for euthanasia and other end-of-life decision-making in Flanders. We found that 73% are general practitioners and nearly all LEIF-physicians have relevant experience in end-of-life care, whether in the form of training (73%), being a member of a palliative team (26%) or having cared for terminally ill patients within the past year (90%). An important part of their work consists of giving information about a wide spectrum of topics in end-of-life care to health care providers as well as to patients and their families. They provide consultation in euthanasia cases but also in other end-of-life decisions. For consultation as a second physician in euthanasia requests most of them were contacted directly by the attending physician, but 27% were not contacted at all over a one-year period. In this period, LEIF-physicians were involved as consultants in 311 euthanasia requests resulting in 221 performed euthanasia cases and administered the euthanasia drugs in 24% of cases.

This is the first study to describe the Belgian consultation service for euthanasia. The response rate of 75% enhances the generalizability of the results for the whole population of LEIF-physicians in Flanders, Belgium. Limitations of the study are that, due to the low absolute number of trained LEIF-physicians, the absolute number included - and hence the statistical power - is rather low, while the retrospective design of this study may have caused recall bias which we can expect to apply in particular to the number of contacts for provision of information on end-of-life care. This study does not include any expert evaluation of the quality of the consultations and the results are entirely self-reported.

An important finding is that LEIF-physicians seem to be well-educated in end-of-life care beyond the LEIF training, which itself covers issues on palliative care as well as on euthanasia (9). Compared to physicians in Belgium from specialities that are more likely to provide end-of-life care, the percentage of LEIF-physicians who attended a postgraduate medical course in palliative care is much higher (20). A quarter were also actually members of a palliative care team. Some authors think that consulting another physician in euthanasia cases is not necessarily a good safeguard of careful practice if the consultant has no competence in end-of-life care (21; 22). While the Belgian law does not specify that the second physician should have such a competence, it does specify that the possibilities of palliative care need to be discussed with the patient. It seems therefore preferable that physicians who work for such a health service are well educated in end-of-life care, which is the case with LEIF-physicians, and also have significant experience. As LEIF-physicians seem not to have significantly more clinical experience than average physicians (23) this could be a possible weakness, although their functioning as consultants will increase their experience. This can benefit a careful euthanasia practice in which the options of palliative care and the choice of euthanasia are well balanced, contributing to the quality of end-of-life decision-making in general.

Our results show that the LEIF secretariat is often bypassed as LEIF-physicians are contacted directly by the attending physician more often than via the secretariat. An advantage of this is accessibility though the attending physicians may always call the same consultant (24), which might be detrimental to independence. The Belgian and Dutch euthanasia laws state that the consulting physician should be independent from patient and attending physician but what is meant by independence is not specified (2)(25). The intention of the law is that the consultant should always be able to formulate an advice independently from the views of the attending physician and the patient. A consultant service with strict guidelines for contact through a

central point, as is the case in the Netherlands, can reduce the chances that a physician will use the same consultant several times. Above that, it can ensure the building-up of experience for all trained consultants.

By sometimes being present when euthanasia takes place and administering the drugs themselves, the involvement of LEIF-physicians goes further than officially outlined by LEIF. As we learned from the commentaries in the open-ended questions, this happens for psychological reasons e.g. the unwillingness of the attending physician to administer the drugs, and for didactic reasons e.g. if the attending physician is inexperienced or unfamiliar with the drugs used. The Belgian law does not specify that the attending physician should perform the act of euthanasia (it can be done by any physician), but the roles between the attending physician and the consultant are not intended to be reversed when the former does not want to perform euthanasia (2).

The numbers of notified euthanasia cases in Flanders (26) combined with our results suggest that LEIF-physicians are involved in more than half of all euthanasia cases in Flanders, assuming that these cases were notified (27). This further stresses the potential importance of a provision such as LEIF and the need for further research to provide insight into the quality of consultations. For other countries considering a law on life-ending on request, a service like LEIF could be beneficial, albeit preferably with strict guidelines concerning contact and consultation procedures. It is also important that the consultants have sufficient education and experience in end-of-life care, although there is no standard as to how much would be sufficient. Providing a service like LEIF where help in end-of-life care issues is freely available can be valuable in any country, regardless of the existence of a euthanasia law, and can contribute towards guaranteeing the competence necessary to the provision of accurate information and support in the range of difficult care situations which can arise at the end of life.

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Part IV

Quality of euthanasia consultations

Watching a peaceful death of a human being reminds us of a falling star; one of a million lights in a vast sky that flares up for a brief moment only to disappear into the endless night forever.

Elisabeth Kübler-Ross

Chapter 7

Quality of consultation with a second physician in euthanasia requests in Belgium: do specifically trained 2nd physicians improve consultation?

Van Wesemael Y, Cohen J, Bilsen J, Smets T, Onwuteaka-Philipsen B, Distelmans W, Deliens L. Quality of consultation with a second physician in euthanasia requests in Belgium: do specifically trained 2nd physicians improve consultation? Submitted.

Abstract

Background

Following the 2002 enactment of the Belgian law on euthanasia, which requires the consultation of an independent second physician before proceeding with euthanasia, the Life End Information Forum (LEIF) was founded which provides specifically trained physicians who can act as mandatory consultants in euthanasia requests. This study aims to assess quality of consultations in Flanders and Brussels and compare these between LEIF and non-LEIF consultants.

Methods

A questionnaire was sent in 2009 to 3,006 physicians likely involved in the care of dying patients.

Results

Response was 34%. Seventy percent of physicians consulted a second physician in a euthanasia request; in 30% this was with a LEIF physician. Overall, the consultant was not a colleague in 42% and not a co-attending physician in 66%. For LEIF physicians, these percentages were respectively 69% and 89%. LEIF physicians more often discussed the request with the attending physician and the family than did non-LEIF physicians (resp. 100% vs 95% and 76% vs 69%). LEIF physicians helped more frequently with performing euthanasia and with filling out the form to officially report the euthanasia case (resp. 44% vs 24% and 46% vs 31%).

Conclusion

In cases of explicit euthanasia requests in Belgium, the consultation of an independent physician by the attending physician is not optimal and can be improved, especially concerning the legally required independence between consultant and treating physician and patient. Training physicians through forums such as LEIF seems to improve the extent to which the legally required due care criteria are met.

Euthanasia (I.e. intentional ending a patient's life at his/her explicit request by a physician) has been legal in Belgium under strict conditions since 2002 (1; 2). The patient must be in a medically hopeless situation of persistent and unbearable physical or psychological suffering as a consequence of a serious and incurable medical condition, which cannot be alleviated otherwise. His or her request must be voluntary, well-considered and repeated. One of the procedural conditions to be followed before considering euthanasia is that the attending physician has to consult a second physician, the consultant, who must be independent from both the attending physician and the patient. This consultant must read the medical file, examine the patient and ascertain that the patient's suffering is unbearable. These are due care criteria to guarantee the safe practice of euthanasia by means of a control mechanism beforehand. If the attending physician considers that the patient will not die in the near future, a third independent physician who is a specialist in the disease, must be consulted and must perform the same tasks as the other consultant. After euthanasia has been performed, the attending physician must report it to the Federal Control and Evaluation Commission on Euthanasia.

In Flanders, the Dutch speaking part of Belgium, a special service called Life End Information Forum (LEIF) was established to provide information and training for health care professionals in end-of-life care matters such as euthanasia (3; 4). The forum also organizes specific training for physicians to obtain the necessary skills and knowledge to act as independent consultants in euthanasia requests (3). On completing the training, these physicians become LEIF physicians. Attending physicians who receive a euthanasia request and who want to consult with an independent physician can call a central telephone number and a LEIF physician is then assigned to them, or they can contact a LEIF physician directly. Consulting specifically with a LEIF physician is not mandatory.
LEIF was created after the enactment of the euthanasia law and a law improving palliative care in Belgium with the intention of educating physicians in end-of-life care and specifically euthanasia, since many did not have any experience in this matter (5). The idea was that if a second physician was needed to appraise a request, it would be better if they had qualifications regarding euthanasia and palliative care. In Belgium, palliative medicine is not a medical speciality and individual universities organize some basic palliative care education, whether or not compulsory, for undergraduate students. The topic of palliative care also receives little to no attention in the regular medical curriculum of most universities in the rest of the world (6-10).

Previously published data on how euthanasia requests are granted or not in Belgium have demonstrated that the advice of the consultant plays a key role in a euthanasia request being granted (11). In this study, we first examined to what extent second physicians were consulted in euthanasia requests in Flanders and Brussels - the area covered by the LEIF physicians – and how often this second physician was a LEIF physician. We also examined which characteristics of the attending physician were associated with consulting a LEIF physician. Secondly, we studied whether the legal requirements were met in the consultation with a second physician and made a comparison between LEIF and non-LEIF physicians. Finally, we compared the consultations between LEIF and non-LEIF physicians in relation to additional non-mandatory tasks performed by the consultant and the outcome of the consultation.

Study design

In March 2009 we sent a questionnaire to 3,006 Belgian physicians by mail. The sample included only registered medical practitioners who worked in Belgium, had graduated in their speciality at least 12 months before the sample was drawn, and were likely to be involved in the care of dying patients. Specialities for which little or no experience in the care for the dying could be expected were excluded. The sample comprised the following specialities: general practice, anaesthesiology, gynaecology, internal medicine, neurology, pulmonary medicine, gastroenterology, neuropsychiatry, psychiatry, cardiology, radiotherapy, and surgery. The sample was stratified for province and speciality and represents a sampling fraction of 9.2%. Since the prevailing privacy law made official registers from the National Institute for Health and Disability Insurance (NIHDI) unavailable to researchers, for each province a random proportional sample was drawn for each speciality from a weekly updated commercial register based on the NIHDI register.

The questionnaire contained a unique serial number. The physicians were instructed in a covering letter to send the questionnaire to an independent lawyer, guaranteeing complete anonymity while allowing for the sending of up to three reminders (12). The anonymity procedure and study protocol were approved by the Ethical Review Board of the University Hospital of the Vrije Universiteit Brussel.

To assess non-response bias, non-responders were sent a one-page form asking them for their reasons for not participating and requesting them to fill in two key questions from the original questionnaire, one about their attitude towards euthanasia, and another about their experience with euthanasia requests (13).

Questionnaire

The pre-structured, eight-page questionnaire with mainly closed-end questions was partly based on one previously used in the Netherlands (14). The questions were adapted to make them appropriate for the Belgian legal context and culture. Concerning their most recent euthanasia request, physicians were asked to answer questions on patient and request characteristics, consultation with a second physician, activities of the second physician and outcome of the request. Questions on quality criteria in accordance with the Belgian due care criteria for consultation were included; these questions were based on a Dutch protocol on consultation in euthanasia requests (15). In the questionnaire, euthanasia was defined as 'the intentional ending of the patient's life at his/her explicit request by the physician'; this definition corresponds to the legal definition of euthanasia in Belgium.

Statistical analysis

For all analyses we selected only the responses from Dutch-speaking physicians from Flanders and Brussels, because LEIF offers its services and trainings in Dutch and provides its services in Brussels and Flanders. Fisher exact tests were performed to compare for LEIF and non-LEIF physicians' independence and activities. P-values that were less than 0.05 were considered statistically significant. The analyses were performed using SPSS 19.0 and StatXact 6.

Response rate and response bias

Of the 3,006 questionnaires sent, 222 physicians were unreachable, deceased or no longer in practice. From the non response survey another 57 were identified as no longer practicing or not having received the questionnaire. As such, there were 2,726 eligible physicians from whom 914 questionnaires were returned, bringing the response rate to 34%. Significant differences between the responders of the survey and responders of the non-response survey were found for attitude toward euthanasia, although both groups strongly agreed on the statement concerning attitude toward euthanasia. No differences between these groups were found concerning having ever received a request.

Physicians receiving euthanasia requests and consulting a second physician

Since 2002, 244 Dutch-speaking physicians from Flanders and Brussels had received a euthanasia request and described the most recent request received. Of these respondents, 170 (70%) had consulted with a second physician (table 1); for the cases where euthanasia was actually performed (N=123) consultation had taken place in 91.9% (not in table). In 51 (30.0%) of the consultations in Flanders and Brussels the consultant was a LEIF physician. General practitioners more often than specialists consulted with a LEIF physician. Physicians between 36 and 50 years old had significantly more often consulted a second physician than had their younger and older colleagues but this was less often a LEIF consultant.

Table 1: number of consultations with a second physician since the law, according to physician's characteristics

	Number of physicians who consulted with a second physician after receiving request in FL and BXL (and % of total physicians in FL and BXL)* Total N= 170 (69.7%)	p-value†	LEIF physician N=51 (30.0%)	Not LEIF physician or not known N=119 (70.0%)	p-value LEIF vs not LEIF‡
Specialty					
General practitioners	118 (69.4)	0.764	42 (35.6)	76 (64.4)	**0.010**
Specialist	51 (30.2)		9 (15.7)	43 (84.3)	
Physician's age					
Younger than 36	17 (10.1)	0.656	5 (29.4)	12 (70.6)	1.000
36-50 years	74 (44.0)	**0.022**	14 (18.9)	60 (81.1)	**0.017**
51-60 years	58 (34.5)	0.149	22 (37.9)	36 (62.1)	0.153
Older than 60	19 (11.3)	0.526	9 (47.4)	10 (52.6)	0.114
Number of terminal patients cared for in 1 year					
0 patients	12 (7.2)	0.202	6 (50.0)	6 (50.0)	0.102
1 to 10 patients	114 (74.5)	0.255	35 (30.7)	79 (69.3)	1.000
more than 10 patients	27 (17.6)	0.850	6 (22.2)	21 (77.8)	0.360
Religiosity					
Not religious	57 (33.5)	0.176	19 (33.3)	38 (66.7)	0.595
Religious	113 (66.5)		32 (28.3)	81 (71.7)	
Training in palliative care or member of palliative team					
Yes	115 (67.6)	0.243	38 (33.0)	77 (67.0)	0.283
No	55 (32.4)		13 (23.6)	42 (76.4)	

* 1 to 17 missing cases. FL= Flanders, BXL= Brussels
† comparison with physicians who did not consult. Significance tested with StatXact, Fisher exact test for statistically significant differences between categories vs all other categories within the variable. Significant differences in bold.
‡ Significance tested with StatXact, Fisher exact test for statistically significant differences between categories vs all other categories within the variable

Quality of consultation

Table 2 lists the extent to which the Dutch criteria for a good consultation were met by all physicians and by LEIF physicians. For all physicians, the consultant was not a colleague of the attending physician in 41.8% of cases and in two thirds of cases the consultant was not a co-attending physician of the patient. The criteria of independence in relation to both the attending physician and the patient were met significantly more often when the consultant was a LEIF physician.
As to additional tasks performed by the second physician, 96.4% had discussed the request with the attending physician, 95.8% had looked into the patient file and 71.3% had talked with the family (Table 3). Almost a third of all consultants had been present when euthanasia was performed, had helped with performing it and had helped in filling out the official reporting form.
All the LEIF physicians had discussed the request with the attending physician compared with 94.9% of the non-LEIF physicians. LEIF physicians had less often discussed the request with another attending physician or with a third physician than had non-LEIF physicians. LEIF physicians had helped the attending physician with performing the euthanasia more often than had non-LEIF physicians and had more often helped with filling out the reporting form.

Table 2: Extent to which the criteria for quality of consultation are met according to whether the second physician is a LEIF physician or not

	All* N=170	LEIF physician (N=51)†	Not LEIF physician (N=119) ‡	p-value LEIF vs not-LEIF
The second physician				
was not a colleague of the attending physician	71 (41.8)	35 (68.6)	36 (30.3)	**<0.0001**
was not a co-attending physician	111 (65.7)	47 (88.7)	64 (53.8)	**<0.0001**
did not know the patient	102 (60.4)	44 (86.3)	58 (49.2)	**<0.0001**
talked to/examined the patient	155 (93.9)	48 (96.0)	107 (93.0)	0.725
made a written report	106 (68.8)	35 (72.9)	71 (67.0)	0.456

* 1 to 16 missing cases
† 1 to 3 missing cases
‡ 1 to 13 missing cases

Advice of the consultant and outcome of the request

The consultant gave a positive advice (i.e. concluded that the conditions for euthanasia were met) in 80.5% (N=136) of all requests (Table 4).
Overall, LEIF physicians significantly more often gave a positive advice (i.e. concluded that the conditions for euthanasia were met) compared with non-LEIF physicians. When asked to what extent the advice of the consultant had influenced their final decision, 60% of respondents indicated that it had to some or to a great extent (56.8% LEIF and 61.4% not LEIF, table 4).
Sixty-eight percent (N=113) of the requests described in Flanders and Brussels resulted in euthanasia. Euthanasia was more often performed when a LEIF physician as opposed to a non-LEIF physician had been consulted but this difference was not significant (76.0% vs 64.1%, p=0.151). Also, euthanasia was more often reported in case the consultant was a LEIF

physician as compared to a non-LEIF physician but this difference was not significant either (86.5% vs 77.3%, p=0.317, not in table).

Table 3: Additional tasks performed by the second physician according to whether the second physician is a LEIF physician or not

	All (N=170)*	LEIF physician (N=51)†	Not LEIF physician or not known (N=119)‡	p-value LEIF vs non-LEIF
The consultant				
had a discussion with the attending physician	161 (96.4)	50 (100.0)	111 (94.9)	0.180
examined the patient file	161 (95.8)	48 (94.1)	113 (96.6)	0.435
had a conversation with the family	114 (71.3)	37 (75.5)	77 (69.4)	0.456
had a conversation with the caring team	80 (51.0)	23 (46.9)	57 (52.8)	0.606
had a conversation with another attending physician	55 (35.9)	10 (20.8)	45 (42.9)	**0.011**
asked for additional advice from a third physician	29 (18.7)	5 (10.4)	24 (22.4)	0.117
was present when euthanasia was performed	45 (30.4)	17 (37.0)	28 (27.5)	0.253
helped with performing euthanasia	46 (30.1)	21 (43.8)	25 (23.8)	**0.022**
helped with filling out the registration form	54 (36.0)	22 (45.8)	32 (31.4)	0.102

* 2 to 22 missing cases
† 1 to 4 missing cases
‡ 1 to 16 missing cases

Table 4: Advice of consultant according to whether the second physician is a LEIF physician or not

	All (N=170)*	LEIF physician (N=51)	Not LEIF physician or not known (N=119)†	p-value LEIF vs non-LEIF
Consultant concluded that conditions for euthanasia were met	136 (80.5)	46 (90.2)	90 (76.3)	**0.037**
Extent to which the judgment of the consultant played a part				
To a great extent	57 (33.5)	20 (39.2)	37 (31.1)	0.478
To some extent	45 (26.5)	9 (17.6)	36 (30.3)	0.124
Hardly	26 (15.3)	11 (21.6)	15 (12.6)	0.157
Not at all	39 (22.9)	11 (21.6)	28 (23.5)	843

* 3 missing cases
† 1 to 3 missing cases

Discussion

This study is the first to examine the quality of consultation between attending physicians and consultants in euthanasia requests in Belgium. We found that in 70% of the euthanasia requests described the attending physician had consulted with a second physician. Of the Dutch criteria for good practice, independence of the consultant, either from the physician or the patient, is the one most often unmet. Life End Information Forum (LEIF) physicians, who had undergone training as consultants in euthanasia requests, were significantly more often independent from the attending physician and from the patient compared with those who had not received the LIEF training. However, they discussed the request less often with other physicians and more often helped in performing the euthanasia.

An important strength of this study is that we used a large sample of physicians from diverse specialities to ask questions about a very sensitive subject. To this end, we used a rigorous sampling and mailing procedure. The questionnaire was comprehensively tested. There are however also some limitations. First, the low response percentage makes it difficult to generalize the results to all physicians in Flanders and Brussels, although analyses of the non-response survey indicate that the sample of responders was comparable to the sample of non-responders regarding having received a euthanasia request. As the survey is retrospective, there may be recall bias, especially for requests from more than a year earlier. Furthermore, the information provided in this survey on the activities of the consultants stems only from the attending physician. Also, it may be possible that LEIF physicians are consulted more often in complex cases or, on the contrary, in cases where it was clear that the due care requirements were met.

We found that 70% of the physicians who had received a euthanasia request had consulted with a mandatory second physician and for the cases where euthanasia was eventually performed this was 92%. A previous study in the Netherlands found consultation to take place in 87% of requests reported by GPs in the period 2000-2002 and in 97% of cases where euthanasia was performed (16). Compared with the Netherlands, consultation in Flanders is thus rather low, especially when taking into account that the percentages in the Netherlands date from the period before euthanasia was legalized. That attending physicians do not always consult a second physician in euthanasia requests can partly be attributed to the fact that in some cases they have already decided not to grant the request and consider they do not need a colleague to confirm their decision. Sometimes, not consulting could also be attributed to a lack of knowledge of the procedure or to the reluctance of attending physicians to be scrutinized by a colleague (17).

Consultants were found not always to have examined or talked to the patient and a written report was not made in one third of consultations. Moreover, independence in relation to the physician and patient seemed often not guaranteed. In one third of cases the consultant was a co-attending physician of the patient. While the law does not describe precisely what is meant by independence (1), being a co-attending physician seems incongruent with the intention of the law that the consultant is able to give independent advice without influence from the attending physician. The fact that attending physicians do sometimes not seek an independent consultant could indicate that they consider the consultation merely a formality.

We also discovered some important differences between consultants who followed a special training, the LEIF physicians, and consultants who did not follow this kind of training. LEIF consultants were more often independent than non-LEIF physicians from the attending physician and the patienti.e.they were more often unacquainted with them. The contact procedure through the central telephone number of LEIF, which is intended to assign a random

LEIF physician (preferably from the region) to the attending physician, seems to create a better guarantee of independence as opposed to simply consulting a colleague from the same hospital or practice. However, this service appears to be called upon in particular by GPs, and much less often by specialists in hospitals who often call on their colleagues, which may be more practical and private but jeopardizes independence. Specialists therefore might especially benefit from a service such as LEIF in order to comply fully with this aspect of the law.

Not only the due care requirements stated in the law or the quality criteria from the Dutch protocol (15) determine the quality of a consultation; there are other tasks that consultants can do which contribute to a more careful and qualitative consultation practice such as discussing the request with the family and other members of the caring team e.g. nurses and physicians. LEIF physicians more often discussed the request with the attending physician and the family than did non-LEIF physicians. On the other hand, they considerably less frequently discuss it with other attending physicians or asked for advice from a third physician. This can be due to the fact that LEIF physicians are more often consulted by GPs, which entails a lower likelihood of there being any other physicians involved. It could also be that LEIF physicians are consulted in less complex cases where additional advice is not needed.

Our results show that consultants also carry out tasks that do not necessarily contribute to the consultation practice, but rather to the careful practice of euthanasia. Sometimes consultants go as far as to be present when euthanasia is performed or even to help with performing it. LEIF physicians were found to help significantly more often with performing euthanasia, probably due to their being better trained than non-LEIF physicians in this process. Although this is not part of their task description, it can be argued that they act as role models for the attending physicians. In previous research, LEIF-physicians indicated that they helped with euthanasia for medico-technical reasons (4). It is useful that a more experienced colleague can show the attending physician how to perform euthanasia, because the medical curriculum does not prepare physicians to deal with such a delicate medical practice. Several authors have stressed the importance of role models in medical education, particularly in end-of-life care, and their influence on ethical decision-making (18-22).
Furthermore, we found that LEIF physicians also more frequently help with filling out the registration form, which certainly contributes to careful practice of the notification procedure (23). It can be helpful if an experienced physician helps the attending physician in certain aspects of the euthanasia procedure, especially if the attending physician is dealing with this for the first time. But the question is if this is the task of the consultant because it could impede the independence of the consultant as he becomes more involved in the process.

Our results show that LEIF physicians more often than non-LEIF physicians give a positive advice on the euthanasia request. A possible explanation is that LEIF physicians may have a more positive attitude towards euthanasia in general. We do not have data to support this hypothesis but not being fundamentally against euthanasia is a prerequisite to being admitted to the LEIF training programme (3). Also, LEIF physicians might be consulted in cases where it is already clear that the due care requirements are met. Another possible explanation is that the non-LEIF consultants, who had not had specific training and probably had less experience, may be more uncertain about the procedure and, hence, more reluctant to give a positive advice. The fact that they more often consult additional physicians than do LEIF physicians, which is not required, may also reflect this uncertainty.

Conclusions
In cases of euthanasia requests in Belgium, the consultation of an independent physician by the attending physician is not optimal and can be improved. Firstly, the proportion of consultations

should be higher and secondly, there should be the required independence between the consultant and attending physician. As we have demonstrated in this study, a service like LEIF can certainly contribute in some respects, by providing independent consultants but also by educating physicians on the consultation procedure in euthanasia requests. Nevertheless, educating future physicians within the regular medical curriculum on end-of-life issues such as decision-making and legal requirements is still needed to further improve the quality of consultations between physicians in euthanasia requests. This kind of education will increase their knowledge and skills and consequently also the quality of care given.

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Chapter 8

Consulting a Trained Physician When Considering a Request for Euthanasia: An Evaluation of the Process in Flanders and The Netherlands

Van Wesemael Y, Cohen J, Bilsen J, Onwuteaka-Philipsen B, Distelmans W, Deliens L. Consulting a Trained Physician When Considering a Request for Euthanasia: An Evaluation of the Process in Flanders and The Netherlands. Evaluation and the Health Professions 2010, 33 (4), 487-513.

Abstract

In Belgium and the Netherlands, consultation of a second independent physician by the attending physician is mandatory in euthanasia cases. In both countries specialized consultation services have been established to provide physicians trained for that purpose. This retrospective study describes and compares quality of consultation of both services based on surveys of attending physicians and those providing the consultation (consultants). While Dutch consultants discussed certain subjects e.g. alternative curative or palliative treatment more often with the attending physician than Belgian consultants, both usually discussed those subjects considered to be necessary for a quality consultation and were independent from patient and attending physician. Over 90% of attending physicians in both countries evaluated the consultant's knowledge of palliative care, patient's disease, and judicial procedure, and their communication skills, as sufficient. Consultation with specialized consultation services seems to promote quality of euthanasia consultations.

Keywords: euthanasia, consultation, health service, referral practice, physician practice

Introduction

Euthanasia, i.e. the ending of one's life by a physician at one's own request, is currently legal in three neighbouring European countries: the Netherlands, Belgium and Luxembourg. In all three countries, the consultation of a second physician is mandatory (1)(2). This means the attending physician must confer with an independent physician, hereafter called the consultant. In Belgium, the law states that the consultant must read the medical file, examine the patient, ascertain that the suffering is persistent and unbearable, and produce a written report. In the Netherlands, the consultant must see the patient and formulate a written advice covering the due care requirements for euthanasia i.e. the voluntariness and well-considered nature of the request, the hopeless and unbearable suffering of the patient, and the lack of any reasonable clinical alternative. In practice, the tasks of consultants in Belgium and the Netherlands are very similar. By requiring the consultation of a second physician, the legislation provides a built-in control mechanism for safe practice prior to the act of euthanasia

This process requires competent and experienced consultants who might be difficult for the physician to find which is why services providing access to specifically trained physicians have been established in Belgium and the Netherlands: Life End Information Forum (LEIF) in Flanders (the Dutch-speaking part of Belgium) and Support and Consultation for Euthanasia in the Netherlands (SCEN) (3)(4). The use of these services is not obligatory and the attending physician is free to find an independent consultant elsewhere. Although there are important differences between the two services deriving from the history and culture of each country, they are both intended to safeguard the quality of consultation and therefore the practice of euthanasia (5). LEIF provides consultation to all physicians, both general practitioners (GPs) and specialists. SCEN was originally available only to GPs, but since 2004 has been available to all physicians.

To help ensure the quality of consultation, a protocol including guidelines was developed for and tested by SCEN consultants in the Netherlands (6). It includes guidance on how to assess whether the legal criteria are met, the requirements for independence between the consultant and the attending physician, the necessary level of expertise of the consultant, the tasks they are required to perform, and the procedure to be followed to reach a decision (6)(7). The law says that the second physician has to be independent, but does not specify what is meant by independent. The guidelines make this more concrete, specifying that the consultant should not work in the same practice of the attending physician, should not be a co-attending physician of the patient and should not know the patient personally. The consultant should possess adequate communicative skills. The tasks of the consultant consist of discussing the patient's request with the attending physician, studying the medical records, seeing the patient and making a written report; the consultant must then assess whether the attending physician has complied with the requirements for prudent practice and then provide advice on whether to proceed or not.

In the Netherlands these guidelines have been tested and were evaluated by the SCEN physicians as useful as a checklist (6). They are intended to be used as a support in consultations and are not legally binding. In Belgium, such a protocol has not been developed, but the LEIF physicians are similarly instructed for consultation during their training using guidelines based on the Dutch protocol. Hence, it can be concluded that LEIF and SCEN physicians apply similar criteria to define a 'good' consultation.

Euthanasia is estimated by large-scale epidemiological studies to take place in about 2% of deaths in Flanders and the Netherlands (8)(9). As consultation beforehand is designed to contribute substantially to the safeguarding of good practice, it is relevant to evaluate the quality of the consultation process in practice. When there are specialized networks of physicians available for consultation in two of the three countries where euthanasia is legalized, it is worthwhile to study how these consultations are held. These results may have implications for both countries, but also for countries where the legalization of euthanasia is subject of debate (10)(11)(12).

The process and quality of consultation with a SCEN physician have already been studied among a representative sample of GPs in the Netherlands based on questionnaires which allow for comparison between consultations with SCEN and non-SCEN physicians (13). This study showed that SCEN contributes to the quality of consultation because SCEN physicians more often met criteria for good consultation than did non-SCEN physicians. However, the consultants' own assessment of the consultations has not been assessed.

Investigations into the number and outcome of consultations with LEIF physicians in Flanders indicate that LEIF physicians are involved in around half of euthanasia cases in Flanders (14) but until now, the characteristics and quality of those consultations have not been assessed.
This study will evaluate and compare the consultations of the Flemish and Dutch euthanasia consultation services, based on information from both the attending physician and the consultant, in terms of the characteristics of the patients requesting euthanasia, how well the consultation met the legal requirements and those of a 'good' consultation as outlined in the SCEN and LEIF training, and the satisfaction of the attending physician with the consultation. Furthermore we will examine and compare how often consultants judged all legal requirements to have been met and agreed that euthanasia should take place, and the outcome of the consultations in relation to the initial attitude of the attending physician towards the request.

Data collection

Descriptive retrospective studies were conducted in Flanders and the Netherlands. In Flanders, in May 2008, the LEIF secretariat mailed a questionnaire to all 132 LEIF physicians who were active at that time, enclosing another for the attending physician, each with a unique serial number. The LEIF physicians were requested to return their own completed questionnaire to the researchers and forward the second questionnaire (with the same serial number) to the attending physician in the last consultation they had taken part in during the previous 12 months (i.e. from May 2007 to May 2008). The attending physicians were also requested to return the questionnaire to the researchers. The researchers communicated the serial numbers to the LEIF secretariat which enabled the sending of up to three reminders in cases of non-response, both to the LEIF physician and the attending physician. This procedure guaranteed the anonymity of all respondents.

In the Netherlands, the registration forms from SCEN consultation between April 2000 and December 2002 were collected. The SCEN physician was then requested to send a questionnaire to the GP who requested the consultation. This GP then returned the questionnaire anonymously to the researchers. Both the questionnaire and the registration form were linked by unique and corresponding serial numbers. For the purpose of this study, only the last registration from each SCEN physician and the relevant GP in 2002 were used as the Belgian data only cover the last consultation of each LEIF physician during a one year period.

Questionnaire

The Belgian and Dutch questionnaires for attending physicians were very similar: both were based on a previous survey for Dutch GPs used in 2000 for the SCEN evaluation study (15). The Belgian questionnaire for LEIF physicians also contained questions from the Dutch registration form for SCEN physicians.

Both the LEIF and SCEN consultants and the attending physicians were asked about their most recent consultation, about their own socio-demographics and in more depth about the last consultation they had taken part in, including the characteristics of the patient, the consultation process and the initial attitude of the attending physician towards the euthanasia request. The attending physicians were also asked to evaluate the consultant and the consultation by means of statements.

Data analysis

Data from the LEIF and attending physicians as well as from the SCEN physicians and Dutch GPs were first merged based on matching serial numbers and then the last registration of each SCEN physician in 2002 was selected.

Descriptive statistics, using SPSS 17.0, were performed to investigate the consultations in Flanders and the Netherlands. Fisher exact tests were carried out with StatXact to test for significant differences between the two countries.

The response was 75% (N=96) for the LEIF-physicians. Sixty-nine LEIF-physicians had performed a consultation during the one-year period, and hence sent a questionnaire to the 69 attending physicians concerned. Fifty-eight percent (N=40) of these attending physicians returned the questionnaire.

In the Netherlands, 433 SCEN physicians had taken part in a consultation in 2002. Only the last registration form per SCEN physician was retained. As all SCEN physicians needed to register all consultations in order to be paid, response was 100%. A total of 433 corresponding questionnaires from the attending physicians were received (response = 100%).

Patient characteristics

In both countries a majority of the patients requesting euthanasia were aged between 60 and 79 years and male (Table 1). Cancer was the main diagnosis in 85.0% of all cases in the Netherlands and in 70.6% in Flanders. Neurological disorders such as Parkinson's disease or paralysis were significantly more often the main diagnosis in Flanders (13.2% versus 4.2% in the Netherlands). In Flanders, in almost 90% of cases there was a written request for euthanasia from the patient and the most common reasons given were suffering without prospect of improvement (79.7%), loss of dignity (49.3%) and general fatigue (44.9%) (not in table; not asked in the Netherlands).

Table 1: Characteristics of the patients requesting euthanasia for which the attending physician consulted a LEIF or SCEN physicians

		% LEIF (N=69)*	% SCEN(N= 433)*	p-value†
Sex				
	Male	54.4	55.6	ns
	Female	45.6	44.4	
Age				
	40-49 years	10.4	9.9	ns
	50-59 years	20.9	21.5	
	60-69 years	29.9	24.5	
	70-79 years	29.9	30.8	
	80 year or older	9.0	13.3	
Diagnosis				
	Cancer	70.6	85.0	< .01
	Multiple Sclerosis/Amyotrophic Lateral Sclerosis	2.9	3.0	ns
	Chronic Obstructive Pulmonary Disease	1.5	3.0	ns
	Psychiatric disorder	4.4	/	/
	General deterioration	7.4	0.9	< .01
	Heart failure	0.0	3.0	ns
	Other‡	13.2	4.2	< .0

* N=69 number of questionnaires returned by LEIF physicians and N= 433 number of questionnaires returned by the attending physician in the Netherlands. Note: the information on the patient characteristics was obtained in Belgium from the LEIF physician and in the Netherlands from the attending physician.
† Calculated with Fisher exact test
‡ Other includes cardiovascular diseases, Parkinson, loss of all limbs, paresis, liver cirrhosis

Consultation characteristics and quality of consultation

In 27.5% of cases the attending physician sought a consultation with a LEIF physician via the LEIF secretariat which then assigned the request to a LEIF-physician. In the other 72.5% the LEIF physician was contacted directly by the attending physician. In 79.7% of consultations the attending physician was a GP. In 23.5% the attending physician (GP or specialist) had also followed the LEIF training (not in table). SCEN physicians were always contacted through a central telephone number because this is mandatory by the SCEN organization and, at the time of the study, this service was only available to GPs (not in table).

In 100% of cases in both Flanders and the Netherlands, the consultant was not a co-attending physician and in 95% of cases did not work in the same practice as the attending physician. In 92.5% (Flanders) and 97.2% (Netherlands), the consultant did not know the patient (Table 2).

In a large majority of cases (90.0% in Flanders and 96.4% in the Netherlands), the physicians discussed the request over the telephone. Significantly more Flemish than Dutch physicians also conferred face-to-face (62.5% versus 37.9% respectively). The topics most frequently discussed during the consultation were the patient's unbearable suffering, the hopelessness of the medical situation (only in questionnaire in Flanders) and the well-considered nature of the request. In Flanders, the topics least frequently discussed were possible alternative curative (5.0%) or palliative (12.5%) treatments, whereas in the Netherlands the least discussed topics were alternative curative treatment (28.5%) and the method of performing euthanasia (42.0%). In a majority of cases, the consultant talked with the patient alone or in the presence of the family (97.5% in Flanders and 83.7% in the Netherlands). The medical records of the patient were studied significantly less often by the LEIF physician than by the SCEN physician (80% versus 93.9% respectively) but patients were medically examined significantly more often by the LEIF physician than by the SCEN physician (40.0% versus 11.9% respectively). Nearly all (98.6%) SCEN physicians produced a written report about the consultation, while this was the case for 82.5% of LEIF physicians.

The appraisals by the attending physicians did not differ significantly between the two countries. A vast majority agreed that the consultant had sufficient knowledge of palliative care, the patient's disease and the judicial procedure (all > 90%, Table 3). Nearly all physicians in Flanders and the Netherlands judged that the consultant was able to assess the patient's competence. More than 91% in both countries agreed that the consultant had adequate communicative skills in his/her contact with the attending physician and the patient or family. More than 96% in both Flanders and the Netherlands judged the quality of the consultation as generally good.

Table 2: Extent to which the criteria for quality of consultation are met by the LEIF and SCEN physicians and details on the discussed topics between physicians

The consultant	LEIF% (N=40)*	SCEN% (N=433)	p-value†
1. does not work in the same practice of the attending physician	95.0	95.2	ns
2. is not a co-attending physician	100	100	ns
3. did not know the patient	92.5	97.2	ns
4. discussed the request with the attending physician via telephone	90.0	96.4	ns
5. discussed the request with the attending physician face-to-face	62.5	37.9	< .01
6. discussed following topics with attending physician:			
the hopelessness of the medical situation	90.0	/	/
the well-considered nature of the request	77.5	87.7	ns
the unbearable suffering of the patient	65.0	95.1	< .001
the voluntariness of the request	60.0	78.2	< .05
the sustainability of the request	60.0	80.0	< .05
the method for performing euthanasia	47.5	42.0	ns
whether it is well-considered to perform euthanasia in this situation	27.5	54.8	< .01
possible alternative palliative treatment	12.5	55.0	< .001
possible alternative curative treatment	5.0	28.5	< .01
7. talked with the patient (alone or with family)	97.5	83.7	< .05
8. talked with family	25.0	41.7	< .001
9. studied the medical records	80.0	93.9	< .01
10. examined the patient physically	40.0	11.9	< .001
11. made a written report	82.5	98.6	< .001

*N=40 number of questionnaires returned by the attending physician in Flanders
For Flanders, the data for criteria 1, 2, 3 and 6 were obtained from attending physician; data for criteria 4, 5, 7, 8, 9 and 10 were obtained from the LEIF physician.
For the Netherlands, the data for criteria 1, 2, 3, 6 and 10 were obtained from attending physician; data for criteria 4, 5, 7, 8 and 9 were obtained from the SCEN physician.
† measured with StatXact Fisher exact test
/ variable not questioned in Dutch study because it is not a criteria for euthanasia by law, unlike in Belgium.

Table 3: Extent to which attending physicians agree or totally agree with statements regarding the expertise and competencies of the consultant

	LEIF% (N=40)*	SCEN% (N=433)	p-value
The consultant was able to give an independent judgment	94.7	98.6	ns
The consultant had sufficient knowledge about palliative care	100	90.6	ns
The consultant was able to assess the patient's competence	100	98.1	ns
The consultant had sufficient knowledge about the patient's disease	97.4	96.8	ns

The consultant had sufficient knowledge about the judicial procedure	100	95.5	ns
The consultant had adequate communicative/social skills in his/her contact with attending physician	95.0	98.4	ns
The consultant had adequate communicative/social skills in his/her contact with the patient (and family)	91.7	95.3	ns
The consultant's activities were adequate to obtain insight into the situation	91.4	93.9	ns
The quality of consultation was generally good	98.4	97.2	ns

*N=40 number of questionnaires returned by the attending physician in Flanders

Course and outcome of the decision process

Eighty two percent of attending physicians in Flanders and 86.0% in the Netherlands were positive towards their patient's euthanasia request at the time they contacted the consultant, meaning they had already decided they would probably or certainly grant the request (Table 4). Thirteen percent of the Flemish and 5.6% of the Dutch attending physicians said they would probably or definitely not grant the request. Around 4% in Flanders and 8% in the Netherlands were undecided at the time they contacted the consultant. In 94.7% (Flanders) and 85.5% (the Netherlands) of cases where the attending physician was positive towards the request, the consultant concluded that the requirements for prudent practice were met and euthanasia eventually took place in 81.5% (44/54, Flanders) and 79.9% (251/314, Netherlands) of these cases (not in table). Where the attending physician was reluctant to grant the request, Flemish consultants judged the requirements to be met in 66.7% of cases while significantly fewer Dutch consultants (20.8%) did. In Flanders, euthanasia eventually took place in a third of cases (2/6) where the consultant judged the requirements to be met but the attending physician had initially been against the request and in the Netherlands there were no such cases. In both cases in Flanders where the attending physician had been undecided and the consultant evaluated the requirements to be met the request was granted, and seven out of sixteen in the Netherlands (not in table).

In seven cases, the LEIF physician judged that the conditions for euthanasia had not yet been met although the attending physician was positive towards the request in three of these. Euthanasia did not take place in two; the outcome of the third case was unknown to the LEIF physician. In 81 cases the SCEN physician judged that the conditions were not met, although the attending physician was positive towards the request in 43 of these. Euthanasia was eventually performed in eight of these cases. The request was rejected for eight patients, eight others withdrew their request, five died before a decision was made, three died before euthanasia was performed and for nine patients, the decision had not yet been taken at the time of the study (not in table).

The second physician no being independent from the attending physician or the patient did not lead to a more according advice nor did it influence the eventual outcome of the request.

LEIF physicians spent on average 3 hours and 15 minutes on each consultation and charged on average 35.5€ (range: from 0€ to 180€) while SCEN physicians took on average 3 hours and 50 minutes; they receive a standard payment of 280€ from the patient's insurance policy after filling out the registration form (not in table).

Table 4: Description of the a priori stance of the attending physician towards the euthanasia request, the judgment of the consultant about the request and the eventual outcome of the request

	LEIF						**SCEN**					
A priori position of attending physician towards the request when consulting the second physician	Positive		Undecided		Negative		Positive		Undecided		Negative	
	82.6% N=57		4.3% N=3		13.0% N=9		86.0% N=369		8.4% N=36		5.6% N=24	
Advice of consultant after consultation	Pos.	Neg.	Pos.	Neg.	Pos.	Neg.	Pos.	Neg.	Pos.	Neg.	Pos.	Neg.
	94.7% N=54	5.3% N=3	66.7% N=2	33.3 % N=1	**66.7%** N=6	33.3% N=3	85.5% N=314	11.7% N=43	44.4% N=16	52.8% N=19	**20.8%** N=5	79.2% N=19
Euthanasia took place	77.2% N=44	0% N=0	66.7% N=2	0% N=0	22.2% N=2	0% N=0	65.6% N=242	2.2% N=8	13.9% N=5	5.6% N=2	0.0% N=0	0.0% N=0

* N=69 for LEIF and N=433 for SCEN. Percentages are within group percentages

Bold underlined are significant differences between SCEN and LEIF (compared with Fisher exact test).

Discussion

This study describes and compares the characteristics of consultations between attending physicians and specialized consultation services in cases of a request for euthanasia in Flemish Belgium (LEIF) and the Netherlands (SCEN). It evaluates the quality of these consultations in terms of the legal requirements for the independence and expertise of the consultant, the mandatory and optional tasks fulfilled, and the eventual judgement of the consultant. We found that both services met most criteria for a good consultation as outlined in the SCEN and LEIF training to a large extent. The satisfaction of the attending physicians with the consultant's knowledge and competence was very high. We also found that the judgement of the consultant is important in decision-making and seems to have a decisive effect on whether euthanasia eventually takes place or not, although the initial attitude of the attending physician towards the request remained an influencing factor.

This study provides insight into the quality of formal euthanasia consultations and their effect on the decision-making process of euthanasia in Belgium (Flanders) and the Netherlands, two of the three countries in the world where euthanasia is legal. It does this by using similar questionnaires, thus enabling comparison between the two. Assessment of the quality of the consultation is not only based on self-reports from the consultants but also on reports on several aspects of the consultation from the physicians who consulted them. This study does however have some shortcomings: despite the good response, the statistical power of the Flemish study is quite weak due to the relatively small number of LEIF physicians in Flanders and the limited number who are actually consulted in euthanasia cases (14). Contrary to the Dutch situation, where the SCEN physicians were paid for doing a consultation which included filling out a registration form, the Flemish physicians received no incentive to complete our questionnaire. Additional non-response from attending physicians further decreased the number of cases available for use in some of the analyses. Another shortcoming relates to the period in which both studies were conducted: the Dutch study was carried out at the time the euthanasia law was enacted, though this was five years after the establishment of a consultation procedure during the period of pseudo-legalization prior to legalization (16), while the Flemish study was conducted five years after legalization. So the Dutch data do not necessarily reflect the current situation. However, at the time of the studies both organizations had been in existence for five years.

Overall, we found that in both countries the quality of the consultations was considered to be good. For instance, consultants met the legally required criterion of independence from both the attending physician and the patient in almost all cases. When discussing the request of the patient with the attending physician, the emphasis for both LEIF and SCEN physicians was on the requirements of due care that are outlined in their euthanasia law: the hopelessness of the medical situation, the unbearable suffering, the voluntariness, sustainability and well-considered nature of the request. In both countries, their expertise, i.e. knowledge of palliative care and of the judicial procedure, was evaluated as sufficient by a large majority of the attending physicians. Almost all attending physicians also agreed that the consultant was able to give an independent judgement and that in the vast majority of cases LEIF, as well as SCEN consultants carried out the tasks required of a consultant, i.e. to read the medical file, discuss the request with the attending physician and the patient and produce a written report.

These positive results suggest that it is advisable to encourage physicians faced with the need to find an independent consultant to utilize a specialist service as it has been shown that, in

Flanders and the Netherlands, they largely fulfil the roles required of them by both the law and the supporting guidelines. Moreover, our results show that their judgement actually influences the outcome of the request and may change the initial attitude of the attending physician. This is shown particularly to be the case when the attending physician is positive towards the request but the consultant is negative. Legislatures which have introduced a condition of consultation into their laws governing physician-assisted death, such as Wallonia (French speaking part of Belgium), Luxembourg and the States of Oregon and Washington in the USA (17)(18), could consider establishing such a network of specialized physicians; it is likely to promote compliance with the legislation, which is a concern for both proponents and opponents of euthanasia (19)(20) and to lead to high-quality consultations ensuring that due care requirements are carefully checked. Countries where there is no law concerning euthanasia or physician-assisted suicide, but where these practices nevertheless take place or legalization is being debated (21)(22)(23) could also consider the establishment of a specialized consultation service as a means of safeguarding good practice.

Although the necessary quality criteria of consultation for both the Flemish and the Dutch service were usually met, we noted differences in practice in the recommended criteria outlined in the Dutch consultation protocol which both organizations use to define good consultation during training (6). During the consultation between the attending physicians and the consultant, some topics are discussed significantly more often in the SCEN consultations than in the LEIF consultations. For example, in the Netherlands almost all physicians discussed the unbearable suffering of the patient while in Flanders only 65% did this. Also, possible alternative curative and palliative treatment is seldom discussed between physicians in Flanders. This is remarkable, considering that LEIF physicians also provide consultation on end-of-life decisions other than euthanasia and that there is explicit emphasis on palliative care during their LEIF-training (14). While this difference may be due to the differences in diagnoses (we found more cancer patients in the Netherlands and more neurological disorders in Flanders), an alternative explanation may be that LEIF, unlike SCEN, has not implemented a protocol or check-list for the consultation. Such a protocol would clarify the tasks of the consultant, resulting in a more standardized consultation that is less dependent on circumstantial or personality-related factors and during which several aspects of the patient's condition and the request are checked systematically. After all, the euthanasia laws in Belgium and the Netherlands do not specify what subjects the consultant should discuss with the attending physician. Either more specifications in the law as to the tasks of the consultant or a more formal protocol, developed by medical professionals, may therefore be helpful. On the other hand, organizing criteria into a protocol may be too rigid to be applicable to every request for euthanasia.

Furthermore, we found small deviations from recommended practice in that the independence of the second physician is not always guaranteed as he or she is sometimes a colleague of the attending physician. While occurring only in a small percentage of cases, this still suggests that a possible problem of collusion between physicians can be present in a considerable number of people requesting euthanasia. Circumstances of time pressure may perhaps preclude total independence in every case, but this deviation from safe practice needs to be confined as much as possible. One measure to do so includes paying more attention during the training of the consultants to independence and the guidelines regarding this topic, especially given the fact that the law provides no concrete directives on this. A formalized financial compensation for LEIF physicians linked to the registration and the written report of the consultation, as is already the case for SCEN physicians could further reduce deviations from recommended practice and would facilitate control over the consultations in Flanders.

Conclusion

In spite of organizational differences between the Dutch SCEN and the Flemish LEIF, we found that physicians from both organizations deliver quality consultations based on the legal criteria and the criteria for good consultation defined in their training programs, which use the Dutch protocol (6). In particular the criterion of independence, which is one of the main reasons for the existence of these consultation services, was fulfilled to a large extent.

It can be concluded, therefore, that physicians in Flanders and the Netherlands are encouraged to make use of these consultation services and that countries with a euthanasia law or regulations on physician-assisted death could consider establishing similar services, in order to safeguard these practices, which, as in the SCEN protocol in the Netherlands, include formal specifications as to the requirements of a euthanasia consultation.

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Part V

Main findings and general discussion

Al onze kennis helpt ons alleen maar om een pijnlijker dood te sterven dan de dieren die niets weten.

Maurice Maeterlinck

Chapter 9

Main findings and general discussion

Introduction

The aim of this dissertation is to study the practice of euthanasia in Belgium. To attain this goal, we asked research questions on the euthanasia requests received by physicians in Belgium, the Life End Information Forum in Flanders and the quality of consultation between physicians in euthanasia requests.

In this general discussion chapter, we will first consider some strengths and limitations arising out of the different studies used to answer our research questions. We will then present a summary of the main findings, after which we will interpret and discuss them in the light of existing knowledge regarding euthanasia and consultation. Finally, we will formulate implications for practice, policy and further research.

Strengths and limitations of the study

LEIF study

For the LEIF study, we selected all physicians who, at the time of the study, had completed two modules of the LEIF training. This selection was made as the director and officer responsible for training at LEIF considered those who had to be functioning actively as LEIF physicians. As such the full population of LEIF physicians was sampled. The questionnaire sent to the 132 LEIF physicians contained questions that were also included in the Dutch registration form for SCEN physicians which is used to monitor their activities and report on them annually (1). This comparability with SCEN is an important strength, as the study was also used to compare LEIF with SCEN physicians, who had already been thoroughly studied (2-4). Moreover, the questionnaire and the mailing procedure were comprehensively tested with several LEIF physicians.

With a fair response rate of 75%, it is safe to assume that our results are generalizable to the whole population of LEIF physicians in Flanders. Analyses for non-response bias showed no significant difference for gender, age, province, speciality and number of completed modules from the LEIF training. However, as the absolute number of LEIF physicians is rather low, so is the absolute number of respondents and hence the statistical power of our study.

The retrospective design also has its limitations. Although we asked LEIF physicians to recall their activities at most a year ago, there may be a recall bias, especially with regard to the number of contacts for the provision of information about end-of-life issues.

As part of the study questionnaires were also sent to physicians who consulted with a LEIF physician. An important limitation here is that the absolute number of respondents was very low (n=40), partly due to a lower response rate than the LEIF physicians (58%) but also to the fact that a questionnaire was only sent to them by the LEIF physician if there had been a consultation between them in the past year. Despite the low statistical power resulting from the method used, an important strength is that we gathered in-depth information on the quality of the consultation with the LEIF physicians from the perspective of the attending physician.

An important strength in the study of the organization and functioning of the LEIF physicians is that we used different methods; a document study to describe the theoretical organization and surveys with LEIF physicians and physicians who made use of them to describe how they have perceived the functioning in practice.

Physician survey

The nationwide physician survey was the first one solely about euthanasia to be conducted in Belgium by means of a rigorous sampling and mailing procedure. In an eight-page questionnaire, a large sample of physicians was invited to answer questions about their attitudes to, their knowledge of and their experience with this controversial practice. Several questions were drawn from surveys previously used in the Netherlands, Australia and six European countries (5; 6). The questionnaire was forward-backward translated from Dutch to French to minimize possible disparities in response due to language differences and was also comprehensively tested with several physicians and a chair of the Federal Control and Evaluation Committee for Euthanasia. To avoid confusion regarding the term euthanasia, we defined it twice in the questionnaire as "intentionally ending the patient's life at his/her explicit request, by the physician". Since the physician was asked to describe the most recent euthanasia request received from a patient, the information provided was not limited to a particular patient population. There may however be an important recall bias in this part of the questionnaire, since we did not put a time limit on the most recent euthanasia request. On the other hand, as euthanasia is an exceptional practice, details about such cases are easier to recall (7). Another potential bias may occur from the fact that the information provided (e.g. reasons for the patient to request euthanasia, tasks performed by the second physician) stems solely from the point of view of the attending physician.

The low response rate (34%) makes it difficult to generalize the results to the whole population of physicians who are likely to be involved in the care of dying patients in Belgium. As the low response rate may be cause for possible responder-bias, we conducted a non-response survey, in which we asked the physicians why they did not fill out the questionnaire, what their attitude was towards euthanasia and whether they had ever received a request. The reasons for not responding are listed in Table 1 (8):

Table 1: Reasons for not responding in the non-response survey by physicians not participating in the main survey (N=583)

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

Not being involved in the care of dying patients, never responding to surveys and not having time to respond to the survey, were the most recurring reasons for not completing the survey.
The responders to the survey, the responders to the non-response survey, and the non-responders to both surveys are presented in Table 2 (8).

Table 2: Comparison of Responders to the Survey with Responders to the Non-response Survey and All Non-responders

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

NA = not available.

Significant differences between responders to the survey and responders to the non-response survey were found for speciality ($p<0.001$) and attitude towards euthanasia ($p=0.001$), although both groups strongly agreed on the statement concerning attitude towards euthanasia. Hence, it seems that the survey was answered by physicians who have a slightly more positive attitude towards euthanasia.

Main findings

Several research questions were addressed in this dissertation and the main findings for each question are summarized below.

The process of euthanasia requests in Belgium

Which physicians likely to be involved in end-of-life care have received a euthanasia request from a patient since the implementation of the euthanasia law? (Chapter 2)

Based on the nationwide physician survey in chapter 2, we found that almost 40% of the Belgian physicians from specialities likely to be involved in end-of-life care had received a euthanasia request since the enactment of the law. Several physician characteristics were associated with a higher chance of receiving a euthanasia request: being older than 36 years old, not being religious, a higher number of terminally ill patients cared for during the last 12 months and having followed training in palliative care or being member of a palliative care team.

What are the main reasons for requesting euthanasia? What are the outcomes of euthanasia requests in Belgium? What patient, physician, process and request characteristics are associated with a request for euthanasia being granted? (Chapter 2)

The most recurring reasons for requesting euthanasia were: suffering without prospect of improvement (72%), loss of dignity (44%), pain (34%) and general weakness (32%).
Of all requests, 48% were granted and performed, 5% were rejected, in 10% patients withdrew their request, 23% died before administration and 13% were still alive at the time the survey was completed.
In bivariate analyses we found that euthanasia was significantly less often granted for patients of 80 years or older (33%), for patients with a psychiatric disorder (0%) or a general deterioration (16%) as main diagnosis and for patients for whom not wanting to be a burden on the family (40%), being tired of living (35%) or depression (16%) were the reasons for requesting euthanasia. The request was also explicitly rejected more often when depression was given as a reason for making the request (21%). Patients older than 80 years withdrew their request significantly more often (17%) than the other age categories. Also patients who indicated dependence as reason for requesting euthanasia withdrew their request more often (17%) as compared to the other reasons given.
In a step-by-step expanded multivariate logistic regression model, we found the following patient characteristics to be predictive for a granted request: suffering without prospect of improvement as a reason for requesting euthanasia, experiencing loss of dignity and having cancer. Depression as reason for requesting euthanasia and being older than 80 years reduced the chance of having a request granted. Older age of the patient and depression as reason for the request were associated with a more negative initial position of the physician towards granting the euthanasia request which in its turn was strongly associated with not granting the request. Adding process characteristics showed that a positive advice from the second physician was highly influential in granting a request.
A psychiatric diagnosis and depression as reason to request euthanasia were strongly associated with refusing a request, indicating that these 'vulnerable' groups are definitely not at a higher risk of receiving euthanasia.

How often does an attending physician consult a second physician in a euthanasia request in Belgium? What is the influence of the second physician on the outcome of the request? (Chapter 2)

Sixty-five per cent (N=235) of responding physicians who described their last euthanasia request since the enactment of the law consulted an independent second physician about the request. Seventy-seven per cent (N= 180) of these consultations resulted in a positive advice from this consultant and of this percentage, 78% ended in euthanasia. None of the euthanasia requests with a positive advice were rejected by the attending physician, compared with 16% for the requests with a negative advice from the second physician. In case of a negative advice, 10% of requests still resulted in euthanasia. When the physician had a positive initial position towards the request, consultation took place in 76% of cases while this was 32% when the physician had a negative initial position towards the request. When the physician was initially undecided, consultation took place in 71% of the cases. In 34% of cases where no consultation took place, the patient died before euthanasia could be performed. It seems safe to assume, based on these findings, that the second physician does have an influence on the outcome.

What are differences between Flanders and Wallonia in terms of attitudes towards euthanasia and the euthanasia law, and in terms of how requests are handled? (Chapter 3)

With only 15% of all officially reported euthanasia cases coming from French-speaking physicians we wanted to investigate differences between Flanders and Wallonia in euthanasia practices.
Our study in chapter 3 indicates several differences in terms of euthanasia attitudes and practices between the Dutch-speaking region of Flanders and the French-speaking region of Wallonia. The acceptance of the practice of euthanasia was not very different between both regions, both in the general public and among physicians, with a somewhat higher acceptance found in Flanders. However, larger differences emerged in the proportion of physicians receiving a euthanasia request since the enactment of the euthanasia law (a higher request rate reported by physicians in Flanders) and in particular in the attitudes and actual practices regarding the due care criteria of the law. Flemish physicians appeared to have a better understanding of euthanasia and the legal obligations of the euthanasia law, and Walloon physicians were both more reluctant to consult a second physician and officially report the euthanasia case to the Federal Control and Evaluation Committee for Euthanasia.
Our findings thus seem to indicate that the relatively low proportion of officially reported euthanasia cases from French speaking physicians is both due to the practice of euthanasia being less frequent in Wallonia and to the fact that Walloon physicians are also less inclined to adhere to the legal safeguards such as consulting a second physician and reporting the euthanasia case.
Based on these findings, it seems warranted to develop information campaigns in Wallonia to better inform physicians (and patients) about the euthanasia law, as such seems to have been done more extensively in Flanders.

The characteristics of LEIF and its LEIF physicians

How is LEIF organized and how is it compared to SCEN in terms of development, aims, tasks and functioning? (Chapter 4)

Similar consultation services were developed in the Netherlands (SCEN) and in Belgium (LEIF) to provide an accessible, independent and qualified second physician in cases of a request for euthanasia.

LEIF was founded in the beginning of 2003 by individual professionals in palliative care and the association 'Right to Die with Dignity'. The founders thought it would be necessary, after the enactment of laws on euthanasia and palliative care, to provide physicians with a point of contact for their questions concerning end-of-life care and for consulting with an independent second physician in case of a euthanasia request of a patient. Also patients and the wider public would be able to ask for information concerning these topics. SCEN (first named SCEA) was founded in 1997 in Amsterdam by the Royal Dutch Medical Association and the Association of General Practitioners with the intention to professionalize the existing practice of consultation.
To become a LEIF physician, physicians have to follow about a total of 24 hours of training modules, spread over several weeks on subjects such as the performance of euthanasia, communication with patient and attending physician and palliative care. Aside from the training modules, there are group meetings called 'intervisions' where LEIF physicians can discuss concrete problems and cases with colleagues. Similar conditions and a comparable amount of training apply to the SCEN physicians.
When physicians require a LEIF consultant, they can call one central telephone number after which a LEIF physician from the region is assigned to them. LEIF physicians then follow the directions as stated in the euthanasia law and are not entitled to a specific financial compensation for their consultation. However, most LEIF physicians charge a regular consultation, which comes on average to 35.5€. They do not have to register the consultation. In the Netherlands, there are telephone numbers per district which physicians can call when they need a SCEN physician. SCEN physicians receive a standard payment of 280€ from the patient's insurance policy after filling out the registration form.
Concerning the financial aspect, our study showed that LEIF received a governmental funding of 20.000€ at the time of its founding, which reduced yearly and ceased in 2008. LEIF still receives some financial support for publishing an informative brochure on end-of-life care. SCEN receives 1.000.000€ annually from the Dutch government.
Though some important differences exist between the LEIF and SCEN initiatives relating to the history and culture of the two countries, they are both intended to safeguard the practice of euthanasia and provide professional support to the attending physicians.

What are the characteristics of LEIF physicians and what training and experience in end-of-life care do they have? With what kind of requests are LEIF physicians contacted with and with what frequency? (Chapter 6)

Based on the study of LEIF physicians, we found that 73% are GPs and nearly all LEIF physicians have relevant experience in end-of-life care, whether in the form of training (73%), being a member of a palliative team (26%), or having cared for terminally ill patients within the past year (90%).
In a period of one year, 73% of the participating LEIF physicians were contacted for consultation in a euthanasia request and most of these contacts were direct, without going via the LEIF secretariat. Almost 30% were contacted for consultation in another end-of-life decision, especially concerning alleviation of pain and other symptoms (103 reported consultations). About 86% of them were contacted to provide information: 2518 requests came from patients and 1491 from physicians. Patients mostly requested information about living wills (n=656), the legal procedure of euthanasia (n=623) and palliative care (n=533) while physicians requested information mainly about the legal procedure or practical performance of euthanasia (n=545).
We can conclude that most LEIF physicians have considerable experience in end-of-life care, whether in their daily practice or under the form of training. In their capacity as LEIF physicians they are contacted both for consultation and for information. However, almost 30% of the LEIF physicians was not contacted for consultation in a one-year period, hence not building up

experience for consultation in euthanasia requests. The LEIF secretariat should strive to allocate consultation requests more evenly among all LEIF physicians.

To what extent has LEIF been successfully implemented in Flanders and Brussels? What are the attitudes of physicians towards consultation in euthanasia requests and on the existence of LEIF? (Chapter 5)

Based on the nationwide physician survey, out of which we selected the Dutch-speaking physicians from Flanders and Brussels, we found that 78% of respondents knew of the existence of LEIF and that one third of the physicians who had ever received a euthanasia request had already made use of LEIF in the past for consultation. This was confirmed in chapter 7 in the last described requests where we found that the second physician was a LEIF physician in 30% of consultations. Almost 90% of respondents indicated a willingness to consult in the future with a LEIF physician in the case of a euthanasia request. Almost 90% felt supported by the idea of being able to consult a LEIF physician in case of a euthanasia request.
GPs had a higher chance of knowing LEIF, having used it and intending to use it in the future than specialists. Physicians younger than 36 more often felt supported by the idea of LEIF and also more often intended to use it in the future than older physicians. Physicians who had cared for more than 10 terminally ill patients in the past year were less likely to feel supported by LEIF or the use the service in the future. Physicians with training in palliative care or who are member of a palliative care team were more likely to know about LEIF and they also more often made use of LEIF in the past than physicians without such taining and experience. Positive attitudes towards the usefulness of consultation in euthanasia requests and towards the necessity of a special training to be able to give an advice as a second physician, were positively associated with knowing LEIF and intention to use it in the future.
The implementation of LEIF was successful in three aspects: knowledge of LEIF, attitude towards LEIF and intention to use in the future. Past use is rather low among physicians who have already dealt with a euthanasia request. GPs in particular seem to frequently consult LEIF. It might be useful for LEIF to promote its services more specifically to specialists, as those physicians are probably used to consult with a colleague from the hospital.

What is the actual involvement of LEIF physicians in euthanasia cases? (Chapter 6 and 7)

In chapter 6, we show that the responding LEIF physicians were asked as a consultant in 355 euthanasia requests in a 1-year period. Of these requests, 311 resulted in an actual consultation. In 92% of these consultations, the LEIF physician evaluated that the due care criteria for euthanasia were met and 68% resulted in euthanasia. In 37% of cases that resulted in euthanasia, the LEIF physician was present when euthanasia was performed. In 27%, they helped with preparation and in 24% he administered the drugs for euthanasia in the presence of the attending physician. About 39% of the responding LEIF physicians indicated that they had helped at least once with the preparation of the drugs for euthanasia and 27% said they had administered the drugs for euthanasia at least once.
In chapter 7, data from our nationwide physician survey in which physicians described the latest euthanasia request they had received show that in 44% of cases where a LEIF physicians was the consulting physician the latter helped with performing euthanasia, compared to in 24% of cases where a non-LEIF physician acted as consulting physician.
It seems that the involvement of LEIF physicians goes further than what the euthanasia law prescribes.

The characteristics and quality of consultations with a second physician

To what extent are the legal requirements of the euthanasia law met during a consultation with a second physician? (Chapter 7)

From the 244 Dutch-speaking physicians from Flanders and Brussels who described their last euthanasia request since the enactment of the law, we learned that 70% of them had consulted with a second physician. For the requests where euthanasia was actually performed (N=123) consultation had taken place in 92% of the cases. Regarding the legally required independence of the consultant towards the attending physician and the patient, we found that in 42% of the consultations, the second physician was not a colleague of the attending physician and not a co-attending physician in 66%. The consultant did not know the patient in 60% of the cases.
In over 90% of cases, the consultant had a discussion with the attending physician, examined the patient file and talked to the patient. They made a written report in 63% of cases.
No significant differences were found between the two regions in Belgium with regard to the independence of the second physician. Walloon consultants more often examined the patient than Flemish physicians, but they less often helped with filling out the registration form (21% vs 42%). No significant differences were found regarding the other tasks of the consultant.
In conclusion, consultation is not optimal as the proportion of cases with a consultation should be higher and the independence of the consultant towards the attending physician and the patient is not always guaranteed.

To what extent does a consultation with a LEIF physician differ from a consultation with a non-LEIF physician in terms of legal requirements and other quality criteria? (Chapter 7)

Based on information from the Dutch-speaking respondents of Flanders and Brussels on the nationwide physician survey, we found significant differences between LEIF and non-LEIF concerning the independence of the consultant towards the attending physician and the patient. The criterion of not being a colleague of the attending physician and of not being a co-attending physician was more often met by the LEIF physicians then by the non-LEIF physician. LEIF physicians also more often did not know the patient than non-LEIF physicians. Both LEIF and non-LEIF physicians discussed the request with the attending physician, talked to or examined the patient in a high number of cases and also made a written report of the consultation in a comparable proportion of cases. LEIF physicians less often had a conversation with another attending physician, compared to the non-LEIF physicians and they more often helped with performing euthanasia. LEIF physicians also helped more often with filling out the registration form as compared to non-LEIF physicians (46% vs 31%, ns).
It seems that LEIF physicians are more often independent towards the attending physician and patient and that they help more often with non-mandatory tasks. Both LEIF and non-LEIF physicians fulfill the tasks required by the law to a similar extent.

How do LEIF and SCEN compare on quality of consultation? (Chapter 8)

We compared concrete cases of euthanasia requests where LEIF and SCEN physicians acted as consultants, based on the study with LEIF physicians and the SCEN registration, and found that the quality of consultations can be considered as good for both countries. In all cases, the consultants from both countries were not co-attending physicians. They were not working in the same practice as the attending physician and did not know the patient in over 92% of cases. LEIF physicians more often discussed the request face-to-face than SCEN physicians (63% vs 38%) instead of only over the telephone (90% vs 96%). As to the content of the discussion between physicians, we found that SCEN physicians more often than LEIF physicians discussed the unbearable suffering of the patient, the voluntariness and the sustainability of the request

and possible alternative palliative treatment. LEIF physicians talked significantly more often to the patient than SCEN physicians but SCEN physicians more often studied the medical file. They also more often made a written report than the LEIF physicians.
From the point of view of the attending physicians, we learned that they were highly satisfied with the expertise and competences of LEIF and SCEN. In all cases, the attending physicians found the LEIF physicians to have sufficient knowledge about palliative care and the judicial procedure. The highest accordance of satisfaction among attending physicians found for SCEN was about the ability of the SCEN physician to give independent advice and his communicative and social skills.
In all cases where LEIF physicians gave a negative advice, euthanasia was not performed, also when the attending physician was initially positive towards the request. A negative advice from the SCEN physician resulted nevertheless in euthanasia in 2.2% of cases when the attending physician was positive towards the request and in 5.6% when the attending physician was undecided about the request.
In conclusion, both LEIF and SCEN deliver good quality consultation, albeit that some differences were found regarding the content of the discussion between physicians and the involvement of the patient and the family. The higher prevalence of written reports by SCEN physicians is in all probability due to the standard financial compensation they receive.

General discussion

The Belgian euthanasia law of 2002 installed due care safeguards in order to guarantee the careful practice of euthanasia (9). One of these safeguards is a control mechanism before euthanasia can be carried out, namely the consultation of a second physician who must be independent from both the attending physician and the patient in order to ascertain that they qualify for euthanasia. Although euthanasia is a medical practice that occurs rarely, even after legalization (10; 11), it is extremely important that the process (including the extent to which legal safeguards are respected) is monitored because of its irreversible nature.
The studies outlined in this dissertation try to describe the process and outcomes of euthanasia requests and describe and evaluate the process of consultation between physicians. Particular attention is paid to the consultations of physicians of the specialized service for professional consultation in euthanasia in Flanders, called Life End Information Forum (LEIF).

The process of euthanasia requests

Physicians receiving euthanasia requests in Belgium

A mortality follow-back study of 2005-2006 via the Sentinel Network of General Practitioners found that in Belgium, approximately one of seven terminally ill patients dying at home under the care of a GP expresses a euthanasia request (12). In a period of 14 months, about one out of five GPs who cared for a terminally ill patient dying at home received at least one euthanasia request (13). From our nationwide survey (chapter 2) we know that about 40% of the responding physicians had received a euthanasia request since the enactment of the euthanasia law in 2002. As can be expected, the proportion receiving euthanasia requests in Belgium is higher than that in countries where no euthanasia law applies (14-17). This might be due to the fact that the general public knows that it is a legally possible option in Belgium, which makes it less precarious to make a request for euthanasia, hence increasing the number of requests. Knowing that there are no sanctions for performing euthanasia if the due care requirements are met, physicians are probably more open to requests and also less reticent to perform euthanasia.

Why patients request euthanasia

Via the nationwide physician survey, we found that reasons for patients to request euthanasia can be medical (e.g. pain), as well as social (e.g. not wanting to be a burden) and psychological (e.g. loss of dignity) and this was found in several other countries such as the Netherlands and the USA (12;14;16-18). The most important reason we found was suffering without prospect of improvement. This was also found in studies in the Netherlands where, as in Belgium, unbearable suffering is a key due care requirement (15;19;20). Pain was an important reason as well to request euthanasia in over one-third of described cases, which is also consistent with previous findings and which might indicate suboptimal pain control (14; 20; 23-25). Our study shows that pain was one of the reasons (but not necessarily the most important one) for requesting euthanasia in 44% of cancer patients. Pain (like breakthrough pain or pain due to bone metastases) is often reported to be very high at the time cancer patients are referred to palliative care, even when these patients were already receiving opioids (26-28). Despite guidelines from the World Health Organization and the Expert Working Group of the European

Association for Palliative Care, and improvements resulting from those guidelines, pain seems to remain undertreated (29-31).

Euthanasia requests and palliative care

Although our survey did not provide information on whether patients requesting euthanasia received palliative care, a significant proportion of requests were made explicitly to and granted by palliative care physicians or physicians with palliative care training. This confirms findings of previous research that euthanasia or euthanasia requests are not related to a lower use of palliative care in Belgium and the Netherlands (32)(24). It also adheres to the view shared by several Belgian experts in palliative care and the Federation for Palliative Care Flanders that euthanasia can be part of good palliative care (33-35). Most respondents from our survey supported this idea as well, since three quarters of them agreed with the statement that life-ending at request of a patient can be part of good end-of-life care. Furthermore, it was found that trained physicians in palliative care were less likely to perceive legalization of euthanasia as having a negative effect on the development of palliative care (8).

To consult or not to consult a second physician?

Consultation with a second physician took place in only 65% of the described requests in Belgium since the enactment of the law (73% in Flanders and Brussels and 50% in Wallonia). This is considerably lower than the 87% consultations found in requests reported by GPs in a Dutch study conducted in 2000-2002, before their euthanasia law was passed (17). In a death certificate study in Flanders examining a representative sample of 6927 deaths occurring in 2007, it was found that 78% of Flemish physicians had discussed the decision to perform euthanasia or assisted suicide with a colleague physician, although this did not necessarily concern the mandatory consultation of a second independent physician (36). The difference in consultation between Belgium and the Netherlands can certainly be attributed to the fact that the Dutch physicians have had experience with this kind of consultation for over 30 years, hence they are very well acquainted with this requirement (37).
One of the reasons why physicians do not consult in Belgium is probably because they had already decided not to grant the request at the moment it is made, e.g. because the physician judges that the due care requirements are not fulfilled. Subsequently, the attending physician does not need a colleague to confirm his decision. We found that consultation took place in only one out of three of these cases where the initial position of the treating physician is not to grant the request, while it took place in 76% of cases where the initial position was to grant the request.
Another possibility is that attending physicians wait to consult a second physician because they first want to convince the patient of an alternative to euthanasia or because they want to postpone the process because of their lack of knowledge about the procedure or about how to perform euthanasia. Also, postponing the process might be linked to the place where the attending physician is working, although our studies did not provide this information. It has been demonstrated, however, that Flemish Catholic healthcare institutions apply palliative filter policies, which means that palliative care options have to be tried first before the treating physician can consider a euthanasia request (38).
Some physicians probably also do not want to be scrutinized by a colleague (39). One in four responding physicians found euthanasia to be a private matter between patient and physician that does not need to be controlled by the Federal Review Committee so some physicians might have the same opinion about the consultation procedure (8).

In the 2007 death certificate study examining a representative sample of deaths in Flanders, a link was found between consultation and reporting of euthanasia: other physicians were consulted significantly more often in reported cases than in unreported cases (40). It seems plausible that this is due to the fact that cases where legal (procedural) requirements were not met are not reported by physicians because they may risk prosecution. However, in a study in the Netherlands, this link was also found and an intention not to report euthanasia was found to be the most important reason for not consulting (41-43).

Quality of consultations

Based on the quality criteria set out in a Dutch protocol and the consultation requirement set out by the Belgian euthanasia law, we found that the overall quality of consultation in Flanders and Brussels is not optimal (44). On most aspects, we also found no significant difference with Wallonia. The independence of the consultant, either from the physician or the patient, was the criterion most often unmet. The fact that attending physicians sometimes do not seek an independent consultant could indicate that they consider the consultation merely as a formality or - in the cases where they already decided to grant the request - they might look for a colleague who confirms their decision. Although it is a legal requirement, writing a report of the consultation was also met by only a small majority of consultants. In other words, these two aspects regarding consultation could be improved.
On a positive note, a large majority of the consultants did fulfil the requirements of discussing the request with the attending physician, talking to or examining the patient and examining the patient file.

Outcomes of requests

Almost half of the euthanasia requests in Belgium described by the respondents of the physician survey ended in actual euthanasia. This is comparable with the 44% granted in the Netherlands over a 12-month period before legislation (17). Only 5% of requests were actually rejected, which is considerably fewer than in the Netherlands (12%) (17). Along with the relatively high number of patients who died before euthanasia could be performed, this might indicate that physicians postpone the decision or that they convince the patient to choose a different option. While we did not ask the attending physicians why they did not grant the request, the information about the advice of the consultant could be an indication: reasons given by consultants in cases of a negative advice were mostly lack of unbearable suffering or the availability of palliative care options. Previous research in the Netherlands has shown that palliative options were indeed most frequently available for patients whose request was finally refused compared to those patients for whom the request had another outcome (45). Another study in Belgium found that euthanasia requests were not granted because patients changed their mind due to family pressure, because the illness was already too advanced, because the patient was not suffering unbearably according to the physician or because the physician thought euthanasia involved too much paperwork (13). Our study showed that physicians were less inclined to grant requests in case of psychosocial motives (e.g. depression, not wanting to be a burden) or existential reasons (e.g. tired of living), than in the case of physical reasons (e.g. pain, dyspnea). It seems that the physicians in our survey still associate suffering more with physical than with psychological symptoms, which is consistent with previous research (17)(21)(46)(47). This finding also implies that physicians take the due care requirement of unbearable suffering seriously, but that they may be too careful when assessing it.

We found that the patient characteristics of suffering without prospect of improvement, loss of dignity, not being depressed, being younger than 80 years and having cancer are predicting factors for having a request granted. These factors seem to influence the initial position of the physician towards the request, after which process characteristics, like the advice of the second physician, become more important.
To a certain level, the life stance of the physician also plays a role in the outcome of a euthanasia request. Not being religious increased the chance slightly of granting a request. Also, religious beliefs strongly influenced the attitude of physicians regarding euthanasia: practising Roman Catholic physicians were less likely to agree that the euthanasia law contributes to the carefulness of end-of-life behaviour and there was a higher refusal for this group to perform euthanasia (8). A similar result was also found in another study in 2002 in six countries by means of a questionnaire sent to physicians from various specialities involved in the care of dying patients. Particularly in Belgium, a strong association was found between life stance and acceptance of the use of lethal drugs: non-religious physicians were more accepting than religious physicians. Non-religious physicians had also more often performed physician-assisted death (48).

Outcomes of requests in vulnerable patients

A repeatedly expressed concern regarding euthanasia i.e. that vulnerable people (older, disabled persons, those with psychiatric disorders) would be more likely to receive it, was not supported by our data (49; 50). On the contrary, being 80 years of age or older decreased the likelihood of a euthanasia request being granted and people in this age group also more often withdrew their request. This is reflected as well in the reported cases of euthanasia in Belgium, in which patients of 80 years and older are under-represented even after controlling for diagnosis and place of death, as in previous death-certificate-based research (51; 52). Also in our study, requests from patients with a psychiatric disorder were never granted and those from persons with general deterioration were granted less often. In other words, our results do not provide evidence for the above-mentioned concern regarding euthanasia for vulnerable people, but they may on the other hand indicate that certain patient groups might not be as assertive as other patient groups in pressing their request or in convincing their physician of their unbearable suffering (53). For instance, previous research found that older patients are less involved in decision-making than younger patients which might indicate suboptimal end-of-life communication (52). Another explanation might be that, due to the discussion about these "vulnerable groups", physicians are more cautious when they handle these requests.

Flanders versus Wallonia

We found significant differences between the regions in Belgium regarding the number of physicians who had received a request since the enactment of the euthanasia law. It seemed that this difference could not be attributed to a lower acceptance of the general public or physicians in Wallonia than in Flanders. The Walloon physicians and general public accepted euthanasia for incurable conditions in people who are suffering to almost the same degree as did Flemish physicians (although Walloon physicians were clearly less positive towards performing euthanasia themselves). A reason might be that the larger public in Wallonia is less acquainted with the euthanasia law and, therefore, patients do not insist on receiving euthanasia. In Flanders, this subject has received ample media attention, among other things with the news coverage of the euthanasia cases of a few famous Flemish persons (for an overview of newspaper articles: (54)). This might have increased patient awareness of the

possibility of euthanasia in Flanders and made it easier for patients to discuss the subject with physicians.

Physicians in Wallonia less often consulted with a second physician. This is probably due to a lack of knowledge of the procedure or to a culturally-based reluctance to adhere to rules. This is also reflected in the more negative attitudes of the Walloon physicians towards the due care requirements of consulting and reporting. Over one third of Walloon physicians thought that euthanasia is a private matter between patient and physician that does not need to be controlled by the Federal Review Committee (8). Due to the presence of LEIF in Flanders, Flemish physicians might be more informed about the euthanasia procedure and might also have easier access to a second independent physician than Walloon physicians, which would explain the higher degree of consultation (55).
Also, Walloon physicians indicated reporting less often to the Federal Control and Evaluation Commission. The unbalance in reporting rate (85% Dutch-speaking and 15 French-speaking) between the two regions (40) hence seems on one hand due to Walloon lay people less often asking for euthanasia and Walloon physicians less often being prepared to grant the euthanasia and on the other hand due to Walloon physicians not knowing the procedural requirements or not wanting to adhere to them.

Life End Information Forum physicians

Who they are

There are some important findings concerning the background of LEIF physicians. They seem to be well-educated in end-of-life care beyond the LEIF training. Compared with physicians in Belgium from specialities that are more likely to be involved in end-of-life care, the percentage of LEIF physicians who had attended a postgraduate medical course in palliative care is much higher (56). A quarter of the LEIF physicians were also actually members of palliative care teams, which can only benefit a safe euthanasia practice since the euthanasia law requires that the patient should be informed about palliative care options (normally by the attending physician). Strangely, on the other hand, our results regarding the handling of euthanasia requests show that LEIF physicians rarely discussed palliative options with the attending physician. They might discuss them more often with the patient, but we do not have information about this.

Their implementation

Based on the study with LEIF physicians and the number of reported cases in 2008, we estimated that LEIF physicians would probably be involved in half of the euthanasia cases in Flanders, assuming that they were all notified. The physician survey we conducted in 2009 and in which we asked physicians to describe their last euthanasia request, showed that LEIF physicians had been involved in 30% of the described consultations since the enactment of the law. Hence, we can assume that their current actual involvement in euthanasia requests lies between 30 and 50% of the euthanasia requests in Flanders.
Regarding the implementation of LEIF in Flanders and Brussels, we found via the physician survey that three out of four aspects of implementation, based on the innovation theory of Rogers, were fulfilled to a high extent: awareness, future use and attitude (57). Past use was fulfilled only by one third of the respondents on the physician survey who had already dealt with a euthanasia request. There is a discrepancy between past use and future use of LEIF, with a high percentage of physicians indicating they would use LEIF in the future. We found however

that past use highly predicts future use so not all physicians indicating they would use LEIF in the future will actually do this. Studies investigating the application of social cognitive theories (eg Theory of Planned Behaviour (58)) on intentions and behaviours of health care professionals have shown that cognitive factors associated with prediction of behaviour were social influences, beliefs about capabilities and consequences, past behaviour and knowledge (59). In other words: in concrete cases of a euthanasia request, it might depend on the physician's perceived capability but also on the context (the concrete case) whether he will consult with a LEIF physician or not.

LEIF was more often consulted by GPs than by specialists and GPs were also more likely to use it in the future. GPs probably do not find a consultant as easily as specialists do, because the latter will look for consultants in their own hospital. This is confirmed by the findings from the reported cases of euthanasia that physicians more often consult with a palliative care physician and additional physicians for patients who died at the hospital than for those dying at home (51). Furthermore, our results imply that physicians who might be less familiar with the legal procedures (e.g. physicians older than 60) or who have less experience in euthanasia practice (e.g. physicians younger than 36), use or intend to use LEIF more often than physicians with more experience and knowledge in euthanasia practice and procedure (e.g. physicians who cared for more than 10 terminally ill patients in the past year).

Their functioning and involvement in actual euthanasia requests

We found that theory and practice are not always in accordance when it comes to the functioning of LEIF physicians. For instance, our results showed that the LEIF secretariat is often bypassed when attending physicians want to get in touch with a LEIF physician. This indicates that LEIF physicians are accessible and known by physicians in Flanders and Brussels. Our results confirmed indeed that most physicians in Flanders and Brussels know of the existence of LEIF, but we do not have information on how well they actually know the contact procedure. By contacting the LEIF physician directly, the attending physician might be inclined to always call this same consultant in case of a euthanasia request, which could be detrimental to the mandatory independence (60).
Another finding that runs counter to the LEIF guidelines and that might compromise the independence of the consultant is the fact that LEIF physicians sometimes perform euthanasia themselves. We learned from the open-ended questions that they do so for psychological or didactic reasons: the attending physician does not want to perform euthanasia or is not experienced enough to perform it safely. The Belgian law does not specify that the attending physician should perform the act of euthanasia (it can be done by any physician), but the roles between the attending physician and the consultant are not intended to be reversed when the former does not want to perform euthanasia (61). The question is hence how the role of the consultant should be fulfilled in practice. Should it be limited to only checking whether the due care requirements are met or could the consultant's role also include guidance, support and some form of education for the attending physician? Our studies show that, in practice, both LEIF and non-LEIF physicians are sometimes present when euthanasia is performed, that they provide practical help with the performance and that they also help with filling out the registration form - all of which are tasks that are not mandatory for the consultant. LEIF physicians could play a specific role herein, as one of their official characteristics is to inform their colleagues. However, their tasks should be demarcated, e.g. they can show a physician how to perform euthanasia, but this should best be limited to a one-time occurrence for every consulting physician. In practice, the consultant has to find a balance between being sufficiently involved to contribute to the good practice of euthanasia, and being adequately independent from both the attending physician and the patient.

The quality of their consultations

In evaluating the quality of consultation of LEIF physicians, an important strength is that we compared it to both non-LEIF physicians in Flanders and SCEN physicians in the Netherlands and that we also have the opinion of attending physicians on this. Based on the criteria set by Dutch experts to operationalize independence (44), we found that LEIF physicians were more often independent from both the attending physician and the patient compared to non-LEIF physicians. Both LEIF and non-LEIF physicians in Flanders and Brussels equally followed the other requirements for consultation to a high extent, except for making the written report, which should be higher for both. LEIF physicians more often performed non-mandatory tasks, like being present when euthanasia was performed or helping with the registration form. Hence, the added value of LEIF physicians lies in the fact that they are more often independent from the attending physician and the patient and by their role in educating physicians on the consultation procedure.
In comparison with the SCEN physicians, we found no significant differences concerning independence, which was fulfilled to a very high degree. Although more pronounced for the SCEN physicians, both LEIF and SCEN physicians put emphasis on discussing the due care requirements outlined in the euthanasia laws with the attending physician: the hopelessness of the medical situation, the unbearable suffering, the voluntariness, sustainability and well-considered nature of the request. On the other hand, LEIF physicians studied the patient file less often and also less often made a written report compared with SCEN physicians. The latter is probably due to the fact that SCEN physicians receive a standard financial compensation upon making a written report. It would probably be helpful if the LEIF physicians would work with a consultation protocol or check-list, like the SCEN physicians do.

As information providers

We found that LEIF physicians are contacted for a considerable number of requests for information on various end-of-life issues. Patients mostly have questions regarding living wills and the legal procedure of euthanasia or palliative care while fellow physicians mostly have questions about the legal procedure or practical performance of euthanasia. Also, almost all Flemish and Brussels physicians responding to our physician survey indicated they felt supported by the idea of being able to appeal to a LEIF physician for information and advice about end-of-life topics. This demonstrates the need of physicians to be informed about this subject, which has also been the conclusion in other research findings (62). Unlike the situation in the Netherlands, where official practical guidelines for physicians exist (63), physicians in Belgium are left to their own devices when it comes to performing euthanasia. Regarding the use of the medication, the National Disciplinary Board of Physicians is of the opinion that physicians should decide by themselves which euthanatics they want to use to perform euthanasia (64). This is because of the framework of therapeutic freedom in which Belgian physicians work (65).

Implications for practice, policy and further research

Practice and policy

As a result of what we found in our studies, a number of recommendations can be formulated to improve how euthanasia requests are handled and how consultations between physicians are conducted.

Improve physician's assessment of psychological and existential suffering in patients requesting euthanasia

In our study on euthanasia requests it became apparent that physicians still direct their attention mostly to physical symptoms in assessing a request. Like many other authors (66) (67), we argue for a holistic approach when caring for the dying and, considering our specific topic of research, also when assessing a euthanasia request. This means, among other things, that physicians should not only have attention for the physical aspects of suffering, but also for psychological and existential suffering. This requires excellent communication and relational skills and emotional self-awareness on the part of the physician (68)(69). These competences should hence receive ample attention in the basic medical curriculum, in post-graduate training in palliative care and in the training provided by LEIF.

Increase knowledge of procedural requirements for euthanasia and stimulate more consultation of second independent physicians

We found that physicians do not consult enough in cases of a euthanasia request, especially in Wallonia. Possible reasons for that are: not wanting to be scrutinized by another physician, postponing the procedure, not knowing the required procedure or already having decided not to grant the request. In all these cases, informing physicians about the procedure could help to incite them to consult in euthanasia requests. Not only should physicians be informed about the procedure in a practical way (e.g. where to find independent physicians, what the tasks of the consultant are), but the information given should probably also aim to change the attitude of physicians towards the consultation and the consultant. They should consider the consultant more as a support in the process, someone they can test their judgement with, rather than as someone whose role is to scrutinize their actions. Information on consultation could be provided by the government by means of brochures spread to hospitals and general practices, via the channels of the Belgian Order of Physicians and/or LEIF and via journals read by a large number of physicians. A particular focus should be on the southern part of the country, as both consultation and reporting rates are low. As LEIF has been active in Wallonia since 2010, this channel could now also be used to inform Walloon physicians about euthanasia and to improve the consultation rate (70).

Improvements in LEIF

When physicians decide to consult, the consultation is not always optimal. Physicians would certainly benefit from consulting an organization like LEIF. Consultation would benefit the independence, the overall quality of consultation and subsequently also the reporting of euthanasia in cases where it is carried out. Hence it is important that the service that LEIF provides, should be maintained. However, LEIF should also set a stricter policy regarding a number of things. Firstly, the contact procedure should be more clearly defined (i.e. all

physicians should go via the central telephone number and not directly contact the LEIF physician) and communicated to the LEIF physicians and the physicians who want to consult with them. Secondly, the organization should also debate with its physicians the educational role they should play regarding performing euthanasia, demarcate this this clearly and communicate this to the population of physicians. Thirdly, LEIF could design a consultation protocol or practical checklist for its LEIF physicians. This consultation protocol should contain a clear listing of the tasks the consultant should or should not perform and a registration procedure could also be linked to every consultation so that quality of consultation can be monitored (44)(71). This would work best if a standard financial compensation were to be given for the entire consultation process, as is the case in the Netherlands. This is however a matter to be decided by the National Institute for Health and Disability Insurance, which would then also act as a control body (72).

Stimulate the use of LEIF physicians

In order to encourage physicians to make use of the LEIF service for consultation, LEIF should continue to promote its services as widely as possible Specialists in hospitals who are used to consulting with colleagues from their own hospital should also be informed about the possibility of consulting a LEIF physician in order to more often guarantee the legally required independence. Support from the government, e.g. in the form of reimbursement of consultation, would formalize LEIF as a consultation service and would therefore also increase the use of their services. LEIF should continue informing physicians about the legal and procedural aspects of euthanasia and should stimulate physicians to comply with the requirements.

Recommendations for the existing regulation

We believe that the process of consultation with an independent second physician is an important safeguarding measure which we would not recommend to change in the law. Not only does a second independent physician provide an objective view on the situation, but by consulting with a colleague the attending physician can share some of the responsibility of his decision (75). Spreading official guidelines about what is meant by independence could be considered. The criteria for good consultation outlined in the Netherlands and used by SCEN physicians (see chapter 7 and 8) could be used to that end (73).
Furthermore, consideration could also be given to whether examining the patient physically, which is a mandatory task for the consultant, is really necessary for good practice and whether this is not too burdensome for the patient.

Further research

Explore the process of handling euthanasia requests

We found in chapter 2 that the decision-making process in euthanasia requests is a complex one in which both patient and physician characteristics play an important role. Therefore, more in-depth studies are needed to gain insight into the reasons why some requests are granted and others are not and why patients withdraw their request. Prospective studies could investigate in which circumstances euthanasia requests are made, why these requests change for some patients (e.g. because they were made aware of different options) and whether there is procrastination by the physician as we have hypothesized.

Whether the patients requesting euthanasia received palliative care at the time of their request and whether being offered good palliative options led to the withdrawal of their request should also be investigated.
Linked to the reasons why requests are not granted, exploration is needed of why the requests of certain populations (elderly, persons with psychiatric disorder) are systematically less often granted. What mechanisms are in force when the requests of patients of 80 years of age and older are not granted? Is it a matter of a lack of assertiveness or are there other factors like place of care (e.g. rest homes)?
Furthermore, investigation is needed into why some physicians do not consult and how they perceive this form of mandatory consultation. Qualitative research in the form of in-depth interviews with physicians could probably answer these questions.

Investigate the perspectives of others

Other people's perspectives on how requests are handled and on consultation with a second physician could be investigated. As in the Netherlands, bereaved family members could be questioned on how they experienced the consultation procedure (74). Patients' perspective on why they request euthanasia could be obtained by means of qualitative methods and by means of prospective studies.

Continue to study LEIF and its impact

In order to have a more precise idea of the involvement of LEIF physicians in performed euthanasia cases in Belgium, a question on whether a LEIF physician was consulted could be added to the registration form for notification to the Federal Review Committee. Such question could also be added to the registration form of the Belgian Sentinel Network of General Practitioners, since a considerable number of GPs consults with LEIF (12).
It should be further explored why physicians would (not) consult with a LEIF physician in the future.
Focus groups with LEIF physicians could also be organized to get more insight in their tasks and to get feedback from the results of the current studies.
Since 2010, LEIF has also been active in Wallonia. A reproduction of the current study on implementation and quality of consultation would be useful to investigate whether LEIF could lead to a higher number of consultations and a higher reporting rate in Wallonia. The information and support provided by LEIF could lead to an improved attitude towards the control mechanisms which are legally required.

Explore the differences between Flanders and Wallonia

Differences between the regions regarding how euthanasia requests are handled and to what extent the procedural requirements are followed should be further explored. We believe that several factors influence these differences: cultural factors in the way euthanasia is perceived by both physicians and the general population, but also practical factors like the distribution of information about this subject. Future research, by means of qualitative methods, should be undertaken to explore why Walloon physicians hold more negative views towards control mechanisms than do Flemish physicians. Differences in views on euthanasia in the wider public should also be studied in more detail.

Until now, a death-certificate-based study in Wallonia has not been possible due to the fact that death certificates registration is delayed in that part of the country. As soon as this lacuna is remedied, it will be possible to study the incidence of euthanasia and consultation in Wallonia.

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Samenvatting van de belangrijkste bevindingen

Inleiding

In België bestaat sinds 2002 een wet die artsen toelaat euthanasie toe te passen op meerderjarige patiënten die ongeneeslijk ziek zijn en uitdrukkelijk en herhaald om euthanasie verzoeken. Een van de controlemechanismen die de wetgever voor de arts verplicht is de consultatie van een onafhankelijke tweede arts vooraleer er met de euthanasie kan worden doorgegaan. Deze tweede arts moet een aantal taken uitvoeren, onder andere zich vergewissen van het ondraaglijk lijden van de patiënt en een verslag opstellen van zijn bevindingen. Een tweede controlemechanisme vindt plaats na de uitvoering van de euthanasie: de behandelende arts dient dit te melden aan de Federale Controle en Evaluatiecommissie Euthanasie.

In Vlaanderen en Brussel werd naar aanleiding van de euthanasiewet een initiatief opgestart, het LevensEinde Informatie Forum (LEIF), dat voorziet in (LEIF)artsen die opgeleid zijn om informatie te geven aan andere artsen en aan het brede publiek over levenseindezorg, maar ook om op te treden als verplichte tweede arts. LEIF was gebaseerd op een gelijkaardig consultatie initiatief in Nederland, namelijk Steun en Consultatie bij Euthanasie in Nederland (SCEN), maar legt een aantal andere accenten in haar dienstverlening.

In Vlaanderen zijn studies op basis van overlijdenscertificaten uitgevoerd die in kaart brengen hoe vaak euthanasie voorkomt. Ook interviews bij zowel Vlaamse als Waalse huisartsen hebben een stukje euthanasiepraktijk beschreven. Daarnaast is er ook een studie geweest van de gemelde euthanasiegevallen, die onder andere een grote discrepantie aangaf tussen Vlaanderen en Wallonië. Tot nu toe zijn er echter nog geen grootschalige studies in België gebeurd die onderzocht hebben hoe artsen omgaan met euthanasieverzoeken, hoe het consultatieproces tussen artsen verloopt en wat de kwaliteit van die consultaties is, in het bijzonder die met de LEIFartsen.

Met dit onderzoek hopen we een duidelijker beeld te schetsen van hoe artsen omgaan met euthanasieverzoeken en trachten we de verplichte consultatie tussen artsen te evalueren. Hiervoor gaan we ook de vergelijking aan met Nederland, een van de 3 landen waar euthanasie wettelijk geregeld is na 30 jaar gedoogbeleid.

Deze doctoraatsthesis is opgebouwd uit drie delen:

- Het omgaan met euthanasieverzoeken door Belgische artsen
- De beschrijving van LEIFartsen als professionele consulenten bij euthanasieverzoeken in Vlaanderen en Brussel
- De kwaliteit van consultatie in Vlaanderen en Brussel en en vergelijking met Nederland

Onderzoeksvragen

In verband met euthanasieverzoeken en hoe ermee omgegaan wordt:

1. Hoe gaan artsen in België om met euthanasieverzoeken?
    - Welke artsen die mogelijks te maken hebben met levenseindezorg hebben een euthanasieverzoek gekregen sinds de implementatie van de wet?
    - Wat zijn de redenen om euthanasie te vragen?
    - Wat zijn de uitkomsten van euthanasieverzoeken in België?
    - Hoe vaak consulteren behandelende artsen een tweede verplichte arts in euthanasieverzoeken in België?
2. Wat zijn de verschillen tussen Vlaanderen en Wallonië aangaande attituden tegenover euthanasie en de euthanasiewet en in hoe artsen omgaan met euthanasieverzoeken?

In verband met de consultatiedienst LEIF:

3. Hoe is de consultatiedienst LEIF georganiseerd en wat is de vergelijking met de gelijkaardige consultatiedienst SCEN in Nederland in termen van ontwikkeling, doelen, taken en functionering?
4. Wat zijn de kenmerken van LEIFartsen en wat is hun rol en betrokkenheid bij euthanasieverzoeken in Vlaanderen?
    - Welke opleiding en ervaring in levenseindezorg hebben de LEIFartsen?
    - Met welke soort vragen en met welke frequentie worden LEIFartsen gecontacteerd?
    - Wat is de werkelijke betrokkenheid van LEIFartsen in euthanasiegevallen?
5. In welke mate is LEIF succesvol geïmplementeerd in Vlaanderen en Brussel?
    - Hoeveel artsen zijn op de hoogte van het bestaan van LEIF?
    - Hoeveel artsen hebben reeds gebruik gemaakt van LEIF voor een euthanasieverzoek?
    - In welke mate voelen artsen zich ondersteun door het idee dat ze beroep kunnen doen op LEIF in geval van euthanasieverzoek?
    - Hoeveel artsen hebben de intentie om gebruik te maken van LEIF in de toekomst?

In verband met de verplichte consultatie:

6. Wat zijn de kenmerken en de kwaliteit van consultaties met een tweede arts bij euthanasieverzoeken?
    - In welke mate zijn de wettelijke vereisten voldaan in de consultatie met en tweede arts?
    - In welke mate verschilt de consultatie met een LEIFarts van die met een niet-LEIFarts op vlak van wettelijke vereisten en bijkomende kwaliteitscriteria?
7. Hoe vergelijkt een consultatie met een LEIFarts zich met een consultatie met een SCEN arts in termen van kwaliteitscriteria?

Gehanteerde methoden

Artsensurvey

In 2009 werd een vragenlijst gestuurd naar een selectie van 3006 Belgische artsen die mogelijks te maken konden hebben met stervende patiënten, namelijk huisartsen, anesthesisten, internisten, neurologen, longartsen, gastro-enterologen, radiotherapeuten, gynaecologen, (neuro)psychiaters, cardiologen en chirurgen. De steekproef werd gestratificeerd naar provincie en specialiteit: voor iedere provincie werd een willekeurige proportionele steekproef getrokken van elke specialiteit. De vragenlijst was gebaseerd op een vragenlijst die eerder al in zes Europese landen en Australië werd gebruikt. Hij werd opgesteld in het Nederlands en vervolgens vertaald in het Frans en terug voor de Franstalig artsen. De acht pagina's lange vragenlijst werd getest bij een tiental experten in palliatieve zorg. Over een periode van zes weken kregen de artsen uit de steekproef tweemaal een vragenlijst en tweemaal een herinneringsbrief toegestuurd. De ingevulde vragenlijsten moesten ze terugsturen naar een advocaat die de anonimiteit van de artsen garandeerde. Er werd eveneens een non-respons onderzoek uitgevoerd waarbij artsen op een pagina moesten aanduiden waarom ze niet hadden deelgenomen aan het onderzoek en ze twee kernvragen moesten beantwoorden (of ze ooit al een verzoek hadden gekregen en een attitudevraag over euthanasie).
Naast sociodemografische gegevens werden artsen ook bevraagd over hun ervaring met euthanasieverzoeken, hun attituden rond consultatie in euthanasieverzoeken en rond LEIF en er werd hen ook gevraagd het laatste euthanasieverzoek van een van hun patiënten te beschrijven. De uiteindelijke respons was 34% (n=914). Meer informatie over deze methode wordt gegeven in hoofdstukken 2,3,6 en 7 en een voorbeeld van de vragenlijst is terug te vinden in de appendix.

LEIF studie

Deze studie bestond uit twee delen:

1. Alle LEIF artsen die minsten twee modules van de LEIF training volgden, kregen een vragenlijst toegestuurd via het LEIF secretariaat waarin ze bevraagd werden over hun activiteiten als LEIFarts gedurende een periode van een jaar en over hun laatste consultatie als tweede of derde arts in een euthanasieverzoek.
2. Indien de LEIFarts een beschrijving had gegeven van zijn laatste consultatie, werd hij gevraagd een andere vragenlijst door te sturen naar de behandelende arts van die laatste consultatie.

Beide artsen werd gevraagd de ingevulde vragenlijst naar de onderzoekers terug te sturen. De respons bij de LEIFartsen bedroeg 75% (n=96) en bij de behandelende artsen was dit 58% (n=40).
Deze studie, die in 2008 werd uitgevoerd, was gebaseerd op de evaluatiestudie van SCEN artsen in Nederland en waar mogelijk werden zoveel mogelijk vragen letterlijk overgenomen om de vergelijking tussen beide landen mogelijk te maken. Meer informatie is te vinden in hoofdstukken 5 en 8 en een voorbeeld van de vragenlijsten is terug te vinden in de appendix.

SCEN registratie

In Nederland moeten SCEN artsen elke consultatie registreren. Tussen april 2000 en december 2002 verzamelde het EMGO Institute for Health and Care Research uit Amsterdam al deze registraties en ze vroegen aan de SCEN artsen om een vragenlijst te sturen naar de huisartsen die beroep hadden gedaan op hun consultatiedienst. De huisartsen stuurde de vragenlijsten

anoniem terug maar ze konden wel gelinkt worden aan de vragenlijsten van de SCEN artsen. Zowel voor de SCEN artsen als voor de huisartsen bedroeg het responspercentage 100%. Voor ons onderzoek werd enkel de laatste registratie weerhouden, aangezien in Vlaanderen ook enkel de laatste consultatie beschreven was. Meer informatie over deze methode is te vinden in hoofdstuk 8.

De drie voorgenoemde studies garandeerden de anonimiteit van de deelnemende artsen door middel van hercodering of door het gebruik van een tussenpersoon. Alle studies werden goedgekeurd door het Ethisch Comité van het UZ Brussel.

European Values Survey

We maakten gebruik van de Belgische data van de Europese studie rond waarden die in 2008 werd uitgevoerd in 47 landen. In elk land werd een representatieve willekeurige steekproef genomen van de volwassen bevolking van 18 jaar en ouder en werden interviews afgenomen. Een van de vragen handelde over euthanasie. In totaal werden 791 mensen uit Vlaanderen en 591 mensen uit Wallonië bevraagd. Meer informatie is terug te vinden in hoofdstuk 3.

Resultaten

Hierna geven we de belangrijkste resultaten uit de verschillende studies weer. Ze werden uitgebreider beschreven in de 7 aparte hoofdstukken.

Het krijgen van verzoeken

In hoofdstuk 2 vonden we dat bijna 40% van de artsen die de artsensurvey invulden, een euthanasieverzoek hadden gekregen sinds de euthanasiewet in voege trad. Artsenkenmerken die geassocieerd waren met het krijgen een verzoek waren: ouder zijn dan 36 jaar, niet gelovig zijn, gezorgd hebben voor een hoger aantal terminale patiënten in het laatste jaar en opleiding gevolgd hebben in palliatieve zorg of deel uitmaken van een palliatief team.

De meest voorkomende redenen om euthanasie te vragen (volgens de artsen) zijn: lijden zonder uitzicht op verbetering (72%), verlies van waardigheid (44%), pijn (34%) en algehele zwakte (32%).

De uitkomsten van verzoeken

Van alle verzoeken werd 48% toegekend en uitgevoerd, 5% werd afgewezen, in 10% van de gevallen trok de patiënt het verzoek terug in, 23% stierf voor de uitvoering en 13% leefde nog op het moment van de bevraging.

In bivariate analyses vonden we dat euthanasie significant minder vaak werd ingewilligd voor patiënten van 80 jaar of ouder (33%), voor patiënten met een psychiatrische stoornis (0%) of met algehele achteruitgang (16%) als hoofddiagnose en voor patiënten die als reden voor verzoek opgaven: niet tot last willen zijn (40%), levensmoeheid (35%) en depressie (16%). Patiënten ouder dan 80 jaar trokken hun verzoek ook vaker in, alsook patiënten die afhankelijkheid opgaven als reden voor verzoek.

In een stapsgewijs regressiemodel vonden we dat de volgende patiëntenkenmerken de kans verhogen dat een verzoek zal worden ingewilligd: lijden zonder uitzicht op verbetering als reden voor verzoek, verlies van waardigheid en kanker als diagnose. Ouder zijn dan 80 jaar en depressie opgeven als reden voor verzoek, zullen de kans op een ingewilligd verzoek verkleinen. Deze laatste twee kenmerken zullen ervoor zorgen dat de behandelende arts eerder een negatieve houding heeft tegenover het verzoek, wat dan ook weer de uiteindelijk uitkomst zal beïnvloeden. Een positief advies van de tweede arts zal dan weer van grote invloed zijn in het inwilligen van een verzoek.

Consulteren van een tweede arts

Vijfenzestig procent van de Belgische artsen die hun laatste euthanasieverzoek beschreven, consulteerden een tweede verplichte arts. Zevenenzeventig procent van die consultaties eindigden in een positief advies van de tweede arts en daarvan eindigden er 48% in euthanasie. Geen enkel verzoek met een positief advies van de tweede arts werd geweigerd, in vergelijking met 16% waar er een negatief advies was. Wanneer de behandelende arts positief stond tegenover het verzoek, vond consultatie plaats in 76% van de gevallen, terwijl dit slechts 32% was wanneer de arts initieel negatief stond tegenover het verzoek. Dit wijst erop dat artsen vooral gaan consulteren wanneer ze zelf al positief staan tegenover het verzoek. In 34% van de gevallen waarin geen consultatie plaatsvond, stierf de patiënt voor uitvoering.

De verschillen tussen Vlaanderen en Wallonië

Onze studie uit hoofdstuk 3 toonde verschillen tussen Vlaanderen en Wallonië aan op verschillende niveaus. De aanvaarding voor euthanasie was niet zo verschillend tussen de twee regio's, zowel in de algemene bevolking als bij de artsen, hoewel het iets hoger was in Vlaanderen. We vonden een groter verschil in de proportie artsen die een verzoek kreeg sinds het in voege gaan van de euthanasiewet: er werden meer verzoeken gerapporteerd door Vlaamse artsen. Er waren ook verschillen in de attituden over de praktijk van euthanasie en over de zorgvuldigheidsvoorwaarden die door de wet verplicht worden (consultatie en melding). Vlaamse artsen schenen beter geïnformeerd te zijn over euthanasie en over de wettelijke vereisten, terwijl Waalse artsen eerder weigerachtig stonden tegenover het consulteren en het melden.

De kenmerken van LEIF en de LEIFartsen en de vergelijking met SCEN

Uit hoofdstuk 4 blijkt dat LEIF en SCEN vergelijkbare initiatieven zijn met een aantal belangrijke verschillen. LEIF werd opgericht in 2003 door individuen met expertise in de palliatieve zorg en de vereniging 'Recht op Waardig Sterven'. De oprichters vonden het nodig, na het in voege treden van de euthanasiewet en de wet op de palliatieve zorg, dat artsen beroep konden doen op professionals met hun vragen rond levenseindezorg en om te consulteren in het kader van een euthanasieverzoek. Ook patiënten en het brede publiek zouden hiervoor bij LEIF moeten terecht kunnen. SCEN werd eerst opgericht in Amsterdam als SCEA in 1997 door de Koninklijke Nederlandse Maatschappij ter bevordering der Geneeskunst (KNMG) en de Vereniging voor Huisartsen met de bedoeling de bestaande praktijk rond consultatie te professionaliseren.

LEIF- en SCEN artsen volgen een vergelijkbare training en doen ook regelmatig aan intervisies waar ze concrete gevallen en problemen kunnen bespreken met elkaar.

Wat de contactprocedure betreft zijn er verschillen waar te nemen in die zin dat LEIF een centraal contactpunt heeft, terwijl er bij SCEN aparte telefoonnummers zijn per district. LEIFartsen moeten hun consultatie niet registreren (wel een schriftelijk verslag voor de behandelende arts) en ze beslissen zelf of ze de consultatie aanrekenen en hoeveel ze aanrekenen. SCEN artsen zijn verplicht hun consult te registreren en deze registratie is verbonden aan een vaste vergoeding van 280€. SCEN wordt nog steeds financieel gesteund voor haar werking door de Nederlandse staat terwijl deze steun bij LEIF herleid is steun voor de druk van een informatiebrochure.

De resultaten uit hoofdstuk 5 geven aan dat er onder de LEIFartsen vooral huisartsen zijn (73%) en dat ze relevante ervaring hebben in palliatieve zorg in de vorm van opleiding (73%), deel uitmaken ven een palliatief team (26%) of zorgen voor terminaal zieke patiënten in het voorbije jaar (90%).

Implementatie van LEIF

In de artsensurvey (hoofdstuk 6) werden de respondenten uit Vlaanderen en Brussel bevraagd over hun kennis van LEIF, hun gebruik ervan, hun attituden erover en hun intentie om het in de toekomst te gebruiken. Daaruit bleek dat 78% van de artsen op de hoogte was van het bestaan en dat 35% van de artsen die reeds een euthanasieverzoek hadden gekregen er al gebruik van gemaakt had. Bijna 90% gaf de intentie aan om LEIF in de toekomst te gebruiken in het geval van een euthanasieverzoek en bijna 90% voelde zich ondersteund door het idee om in zulke

gevallen beroep te kunnen doen op een LEIFarts.

Huisartsen maakten meer kans dan specialisten om LEIF te kennen, om er gebruik van gemaakt te hebben en om het te gebruiken in de toekomst. Artsen jonger dan 36 jaar voelde zich vaker ondersteund door het idee om op LEIF beroep te kunnen doen en hadden ook vaker de intentie om er beroep op te doen in de toekomst dan oudere artsen. Artsen die voor meer dan 10 terminaal zieke patiënten in het voorbije jaar zorgden maakten minder kans om zich ondersteund te voelen door een dienst al LEIF of om het in de toekomst te gebruiken. Positieve attituden tegenover het nut van consultatie en het volgen van een speciale opleiding om te kunnen consulteren, waren ook geassocieerd met het op de hoogte zijn van LEIF met de intentie om er in de toekomst gebruik van te maken.

Betrokkenheid van LEIFartsen in euthanasie en andere levenseindevragen

Uit de bevraging in hoofdstuk 5 blijkt dat in een periode van een jaar 73% van de bevraagde LEIFartsen gecontacteerd werd om als consulent op te treden bij een euthanasieverzoek en meestal gebeurde dit via rechtstreeks contact en niet via het secretariaat van LEIF. Ze traden op als consulent in 355 euthanasieverzoeken. In 92% van die consultaties gaven ze een positief advies en 71% eindigde in euthanasie. In 27% van de gevallen had de LEIFarts geholpen bij de voorbereiding en in 24% had de LEIFarts zelf de middelen voor euthanasie toegediend.

Uit dezelfde bevraging blijkt dat 86% van de LEIFartsen werd gecontacteerd om informatie te geven: 2518 vragen kwamen van patiënten en 1491 kwamen van artsen. Patiënten vroegen vooral om informatie rond wilsverklaringen (n=656), de juridische procedure voor euthanasie (n=623) en palliatieve zorg (n=533) terwijl artsen vooral naar informatie vroegen rond de juridische procedure voor euthanasie (n=545).

De kwaliteit van consultaties

In hoofdstuk 7 werd de kwaliteit van consultatie onderzocht bij de respondenten uit Vlaanderen en Brussel die hun laatste euthanasieverzoek hadden beschreven. Zeventig procent van hen had geconsulteerd met een tweede arts. In de gevallen waar euthanasie uiteindelijk was uitgevoerd, had consultatie plaatsgevonden in 92%. In verband met de wettelijk verplichte onafhankelijkheid vonden we dat de consulent geen collega was van de behandelende arts in 42% van de gevallen en geen medebehandelaar in 66%. De consulent kende de patiënt niet in 60% van de gevallen.

In meer dan 90% van de gevallen had de tweede arts een gesprek met de behandelende arts en onderzocht hij of sprak hij met de patiënt. Een schriftelijk verslag werd gemaakt in 63%.

Na vergelijking van bovenstaande resultaten met consulterende artsen uit Wallonië, werden er geen significante verschillen gevonden tussen de twee gewesten wat de onafhankelijkheid van de tweede arts betreft. Waalse consulenten onderzochten de patiënt wel vaker dan hun Vlaamse collega's maar ze hielpen minder bij het invullen van het meldingsformulier voor de controlecommissie (wat ook geen verplichte taak is).

Op basis van de resultaten uit Vlaanderen en Brussel werd een vergelijking gemaakt tussen LEIFartsen en niet-LEIFartsen. Vooral betreffende de onafhankelijkheid van de consulent werden significante verschillen waargenomen. De criteria van geen medebehandelaar te zijn of geen collega van de behandelende arts, was vaker voldaan bij de LEIFartsen dan bij de niet-LEIFartsen. LEIFartsen kende de patiënten ook vaker niet dat de niet-LEIFartsen. Beide consulenten bespraken het verzoek met de behandelende arts, spraken of onderzochten de patiënt en maakten een schriftelijk verslag van de consultatie in een vergelijkbaar aantal

gevallen. LEIFartsen hadden minder vaak een gesprek met een andere behandelende arts, maar hielpen dan wel vaker bij de uitvoering van euthanasie. Ze hielpen ook iets vaker met het invullen van het meldingsformulier.

De vergelijking in kwaliteit met Nederland

Wanneer we de consultaties van een jaar van LEIF- en SCEN artsen vergelijken (hoofdstuk 8), blijkt dat de kwaliteit ervan globaal genomen goed is. In alle gevallen waren noch de LEIFarts of de SCEN arts medebehandelaar van de patiënt. Ze werkten niet in dezelfde praktijk als de behandelende arts en kenden de patiënt niet in meer dan 92% van de gevallen. In vergelijking met de SCEN artsen bespraken de LEIFartsen het verzoek vaker in persoon met de behandelende arts (63% vs 38%) dan enkel via de telefoon (90% vs 96%). SCEN artsen bespraken wel vaker dan LEIFartsen het ondraaglijk lijden van de patiënt, de vrijwilligheid en duurzaamheid van het verzoek en mogelijke alternatieve palliatieve opties. LEIFartsen spraken vaker met de patiënt terwijl SCEN artsen vaker het medisch dossier inkeken. SCEN artsen stelden ook vaker een schriftelijk verslag op.

In beide landen waren de behandelende artsen tevreden over de expertise en competenties van de tweede arts. In alle gevallen vonden de behandelende artsen dat de LEIFartsen voldoende kennis hadden over palliatieve zorg en over de juridische procedure van euthanasie. Bij SCEN waren de behandelende artsen het meest tevreden over hun vermogen om een onafhankelijk advies te geven en over hun communicatieve en sociale vaardigheden.

Discussie

Hoofdstuk 9 van de doctoraatsthesis beschrijft de sterktes en zwaktes van de gehanteerde methodes in de onderzoeken. Verder wordt ook uitgebreid ingegaan op de resultaten en op de interpretatie ervan. Op het einde van het hoofdstuk worden er ook aanbevelingen gedaan voor het beleid en voor toekomstig onderzoek. Hieronder beschrijven we de belangrijkste discussiepunten.

Verloop van euthanasieverzoeken

Uit onze resultaten blijkt dat de redenen waarom patiënten euthanasie vragen zowel medisch, sociaal als psychologisch kunnen zijn. Dit gegeven vindt men ook in andere landen terug. Lijden zonder vooruitzicht op verbetering bleek, net als in Nederland, de voornaamste reden te zijn om euthanasie te verzoeken. Dit is niet zo verwonderlijk gezien het een wettelijke voorwaarde is voor euthanasie. Opvallend is toch dat pijn in een derde van alle gevallen en in 44% van de kankerpatiënten reden was tot verzoek. Dit wijst erop dat pijn nog steeds niet optimaal behandeld wordt, ondanks onder andere internationale richtlijnen van de Wereldgezondheidsorganisatie en een expertengroep van de Europese Associatie voor Palliatieve Zorg.

Of de patiënten uit onze bevraging palliatieve zorgen kregen, kunnen we niet achterhalen uit onze resultaten, wel dat een significante proportie verzoeken werd gemaakt bij en ingewilligd door artsen die werkzaam zijn in een palliatief team of die bijkomende opleidingen in palliatieve zorg hebben gevolgd. Dit wijst erop dat euthanasieverzoeken niet gelinkt zijn aan het lager gebruik van palliatieve zorgen en sluit aan bij de visie van verschillende experten en van de Federatie Palliatieve Zorg dat euthanasie kan deel uitmaken van goede palliatieve zorg. De respondenten uit onze artsensurvey sluiten zich ook aan bij deze visie aangezien driekwart van hen het eens was met de stelling dat euthanasie kan deel uitmaken van goede levenseindezorg.

Na het krijgen van een euthanasieverzoek, gaat slechts 65% van de artsen (73% in Vlaanderen en Brussel en 50% in Wallonië) een tweede arts opzoeken om te consulteren. Dat is beduidend minder dan de 87% consultaties die in Nederland werd gevonden onder huisartsen. Dit verschil kan te maken hebben met het feit dat de Nederlandse artsen meer dan 30 jaar ervaring hebben met de praktijk van consulteren en dus meer vertrouwd zijn met deze controleprocedure.

Een van de redenen waarom artsen in België niet consulteren is allicht omdat ze al van in het begin beslist hebben dat ze het verzoek niet zouden inwilligen, bijvoorbeeld omdat ze oordelen dat niet aan alle voorwaarden voor euthanasie is voldaan. We vonden dat consultatie plaatsvond in slechts een derde van de gevallen waarbij de behandelende arts initieel negatief stond tegenover het verzoek. Sommige artsen wensen mogelijks ook liever niet gecontroleerd te worden door een collega. Uit onze bevraging bleek immers dat een vierde van de respondenten vond dat euthanasie een privézaak is tussen arts en patiënt. Eerder werd ook al een link gevonden tussen consulteren en melden dus mogelijks consulteren artsen ook niet omdat ze vooraf al beslist hebben dat ze de euthanasie niet zullen melden. Een andere reden waarom artsen niet consulteren kan ook zijn dat ze de procedure willen uitstellen omdat ze er onvoldoende kennis over hebben en/of omdat ze de patiënt proberen te overtuigen van een andere optie. In ander onderzoek werd ook al aangetoond dat Vlaamse Katholieke ziekenhuizen een beleid voeren met palliatieve filter voor euthanasie waarbij artsen in het ziekenhuis verplicht worden om eerst een palliatief team te raadplegen alvorens de arts het verzoek overweegt.

Kwaliteit van consultaties

Uit ons onderzoek blijkt dat de kwaliteit van consultatie tussen artsen niet optimaal is. De criteria die vanuit Nederland werden aangegeven om onafhankelijkheid te operationaliseren, waren het minst vaak voldaan. Het feit dat artsen soms geen onafhankelijke arts zoeken, kan erop wijzen dat ze consultatie maar als een formaliteit zien of dat ze vooral een consulent zoeken die hun beslissing bevestigt. Hoewel het een wettelijke vereiste is, werd het schrijven van een verslag ook maar door een kleine meerderheid van de consulenten gedaan. Dit zijn dus twee aspecten die in België nog kunnen verbeterd worden, o.a. door artsen beter te informeren over de procedure en over het nut van consultatie.

Het is wel zo dat consulenten in grote mate de vereiste vervullen van het verzoek te bespreken met de behandelende arts en van de patiënt te spreken of te onderzoeken.

Uitkomsten van euthanasieverzoeken

Bijna de helft van de beschreven verzoeken mondde uit in euthanasie, wat vergelijkbaar is met Nederland. Slechts 5% werd effectief geweigerd, in vergelijking met 12% in Nederland. Samen met het hoog aantal patiënten dat stierf voor de uitvoering van euthanasie kan dit erop wijzen dat artsen liever het beslissingsproces rekken dan dat ze een verzoek expliciet weigeren. Hoewel we de artsen niet gevraagd hebben waarom ze het verzoek weigerden, blijkt uit de negatieve adviezen van de consulent dat er geen sprake was van ondraaglijk lijden of dat er nog palliatieve opties mogelijk waren. Uit ander Belgisch onderzoek blijkt dat verzoeken niet werden ingewilligd omdat patiënten al te ziek waren, omdat ze niet ondraaglijk leden of omdat ze hun verzoek terug introkken door bv. familiale druk. We vonden ook dat artsen het verzoek minder vaak inwilligden als de patiënt psychosociale redenen had opgegeven voor het verzoek (bv. depressie, niet tot last willen zijn) dan als de patiënt fysieke redenen gaf (bv. pijn, benauwdheid). Dit geeft aan dat artsen voorzichtig omspringen met verzoeken, maar misschien ook dat ze lijden vooral nog associëren met fysiek lijden dan met psychisch lijden.

Patiëntenkenmerken die geassocieerd waren met het inwilligen van een verzoek waren: jonger zijn dan 80 jaar, kanker als diagnose hebben, lijden zonder uitzicht op verbetering en verlies van waardigheid als reden voor verzoek en geen depressie hebben. Deze factoren beïnvloeden hoe een arts initieel tegenover het verzoek zal staan, waarna proceskenmerken zoals het advies van de tweede arts, doorslaggevend zullen worden. De levenshouding van de behandelende arts speelt voor een stuk ook mee in het beslissingsproces: niet gelovig zijn verhoogde de kans op het inwilligen van het verzoek. Dit vindt men ook terug in andere Europese landen waar uit onderzoek bleek dat Rooms-katholieke artsen meer weigerachtig stonden tegenover het uitvoeren van euthanasie.

Verder blijkt ook dat bepaalde patiëntengroepen, zoals de ouderen dan 80, minder vaak euthanasie krijgen en ook vaker hun verzoek intrekken dan de personen jonger dan 80. Mogelijks kan dit te wijten zijn aan een gebrek aan assertiviteit in deze patiëntengroep ofwel gaan artsen voorzichtiger om met deze "kwetsbare" patiëntenpopulaties omdat tegenstanders van euthanasie menen dat deze groepen bij legalisering makkelijker euthanasie zouden krijgen of zonder dat ze erom verzocht hebben.

Vlaanderen versus Wallonië

We vonden belangrijke verschillen tussen Vlaanderen en Wallonië inzake het aantal verzoeken dat artsen krijgen sinds de euthanasiewet in werking trad. Dit kon niet worden toegeschreven aan een lagere acceptatiegraad van euthanasie door de Waalse artsen en het Waalse publiek

(hoewel het iets lager was dan Vlaamse artsen en de Vlaamse bevolking). Mogelijks is het wel zo dat zowel de Waalse artsen als het publiek minder vertrouwd zijn met de wet en dat patiënten in Wallonië er daarom ook minder om verzoeken. In Vlaanderen heeft dit onderwerp reeds veel aandacht gekregen in de media onder de vorm van nieuwsfeiten (bekende Vlamingen die euthanasie kregen) en documentaires. Dit kan ervoor gezorgd hebben dat Vlamingen dus meer op de hoogte zijn, maar ook dat het daardoor meer bespreekbaar is geworden tussen patiënt en arts.

Waalse artsen consulteren minder vaak met de verplichte tweede arts dan Vlaamse artsen. Dit is hoogstwaarschijnlijk enerzijds te wijten aan een gebrek aan kennis over wat euthanasie is en de wettelijke procedures er rond en anderzijds aan een cultureel bepaalde terughoudendheid om zich te houden aan regels. Waalse artsen bleken meer negatief te staan tegenover de controlemechanismen van de wet en een derde van hen vond dat euthanasie een privé aangelegenheid is tussen arts en patiënt. Door de aanwezigheid van LEIF in Vlaanderen is het ook mogelijk dat Vlaamse artsen beter geïnformeerd zijn over de euthanasieprocedure en hebben ze allicht ook makkelijker toegang tot een onafhankelijke consulent dan hun Waalse collega's.

Verder bleken de Waalse artsen hun euthanasiegevallen ook minder vaak te rapporteren aan de Controlecommissie. Het disproportionele meldingspercentage (85% Nederlandstalig en 15% Franstalig) schijnt dus te wijten zijn aan verschillen op verscheidene niveaus: Waalse artsen krijgen minder verzoeken en zullen ze ook minder vaak inwilligen door oa gebrek aan kennis en door een terughoudendheid om de procedurele vereisten te volgen. Vervolgens zullen ze ook iets minder vaak melden.

LEIFartsen

Uit onze resultaten blijkt dat de LEIFartsen gekend zijn bij een groot deel van de Vlaamse en Brusselse artsen maar dat ze nog niet zo vaak gebruikt worden door artsen die reeds te maken hadden met een euthanasieverzoek (35%). Ze worden naar schatting ingeschakeld voor 30 à 50% van de euthanasiegevallen in Vlaanderen en Brussel. Wel geven bijna 90% van de artsen aan dat ze LEIF in de toekomst zouden gebruiken. Of ze dit ook echt zullen doen, hangt allicht van situationele factoren af (bv. het concrete geval, de beschikbaarheid van een LEIFarts in hun omgeving, enz). Dit aspect van implementatie (toekomstig gebruik) zou dus verder kunnen onderzocht worden.

Huisartsen bleken vaker beroep te doen op LEIFartsen en zouden het ook vaker in de toekomst doen dan specialisten. Dit komt allicht omdat zij minder makkelijk een consulent kunnen vinden, in tegenstelling tot specialisten die in ziekenhuizen werken en daar ook een consulent zullen raadplegen. Verder tonen onze resultaten ook aan dat artsen die mogelijks minder vertrouwd zijn met de wettelijke euthanasievereisten (bv. artsen ouder dan 65) en artsen die minder ervaring hebben met euthanasie (bv. artsen jonger dan 36) meer gebruik maken van LEIF en ook meer de intentie hebben voor de toekomst dan artsen die wel ervaring en kennis hebben hierover (bv. artsen die in het afgelopen jaar voor meer dan 10 terminale patiënten zorgden). LEIF verspreid dus best informatie over haar werking zo breed mogelijk om zo veel mogelijk artsen te bereiken.

We vonden dat de meeste LEIFartsen los van de LEIF training, goed opgeleid schijnen te zijn in levenseindezorg. In vergelijking met andere Belgische artsen die mogelijks te maken hebben met terminale patiënten, hadden LEIFartsen vaker een postgraduaat in de palliatieve zorg gevolgd. Een kwart van de LEIFartsen maakt ook deel uit van een palliatief team. Deze ervaring

kan alleen maar bevorderlijk zijn voor een goede consultatiepraktijk in euthanasieverzoeken.

Wat de werking van de LEIFartsen betreft, vonden we dat theorie en praktijk niet altijd in overeenstemming zijn. Zo blijkt dat artsen vaak rechtstreeks de LEIFarts contacteren in plaats van via het LEIF secretariaat te gaan. Positief hieraan is dat de LEIFartsen dus wel makkelijk bereikbaar zijn. Anderzijds kan het wel het risico met zich meebrengen dat een behandelende arts steeds dezelfde LEIFarts contacteert en dat de onafhankelijkheid op die manier vermindert. Wat ook de onafhankelijkheid kan belemmeren is het feit dat LEIFartsen soms aanwezig zijn bij de uitvoering van euthanasie of zelf de euthanasie uitvoeren. Uit de open vragen weten we dat ze dit doen om psychologische of didactische redenen (bv. de behandelende arts wil het niet uitvoeren of weet niet hoe het moet). De Belgische wet verbiedt niet dat de tweede arts zou aanwezig zijn bij de euthanasie maar het is niet de bedoeling dat de rollen tussen beide artsen verwisseld worden als de behandelende arts geen euthanasie wil uitvoeren. De vraag is dus hoe de rol van de consulent in de praktijk moet worden ingevuld: moet hij beperkt worden tot nagaan of de voorwaarde van lijden voldaan is of zou zijn rol ook een bepaalde mate van steun, leiding en een vorm van educatie kunnen inhouden? Onze studies geven aan dat zowel LEIF als niet-LEIFartsen in de praktijk soms aanwezig zijn bij euthanasie, soms helpen bij de uitvoering en ook helpen bij andere taken waartoe ze niet verplicht zijn (bv. helpen bij invullen van meldingsformulier). LEIFartsen kunnen hierin wel een specifieke rol spelen, aangezien een van hun officiële taken is om artsen te informeren (wat ook uit onze resultaten blijkt). Dit moet dan wel duidelijk afgebakend worden door de organisatie van LEIF. In de praktijk zou de consulent een evenwicht moeten vinden tussen voldoende betrokken zijn om bij te dragen tot een goede euthanasiepraktijk en voldoende onafhankelijk zijn tegenover de behandelende arts en de patiënt.

Tot slot blijkt uit onze resultaten dat de kwaliteit van consultatie met LEIFartsen globaal als goed kan worden beschouwd. Een sterkte in onze beoordeling hierover is dat we zowel met niet-LEIFartsen in Vlaanderen als met SCEN artsen in Nederland hebben kunnen vergelijken. Daarnaast hebben we ook de mening van behandelende artsen hierover kunnen vragen. We vonden dat LEIFartsen vaker onafhankelijk waren tegenover de behandelende arts en de patiënt dan niet-LEIFartsen. De andere verplichte vereisten volgden ze ook in hoge mate, maar hier was geen verschil waar te nemen met de niet-LEIFartsen. Een andere toegevoegde waarde aan de LEIFartsen is dat ze vaker helpen met taken die niet verplicht zijn en waaruit hun educatieve/informatieve rol blijkt. In vergelijking met de SCEN artsen is het wel zo dat LEIFartsen minder vaak het patiëntendossier inkeken en ook minder vaak een schriftelijk verslag maakten. Dit laatste kan te maken hebben met het feit dat SCEN artsen een standaard financiële compensatie krijgen na het schrijven van hun verslag.

Appendices

Survey for LEIF physicians

Survey for attending physicians who consulted with a LEIF physician

Nationwide survey in Dutch

Nationwide survey in French

Curriculum vitae and list of publications

eifartsen

MELC
monitoring quality of end-of-life care

LEIFnr: ____

A	**De volgende vragen gaan over uzelf**	
1	**U bent**	☐ vrouw ☐ man
2	**Wat is uw leeftijd?**	☐ < 30 jaar ☐ 40 - 49 jaar ☐ 60 jaar of ouder ☐ 30 - 39 jaar ☐ 50 – 59 jaar
3	**In welke regio/provincie bent u hoofdzakelijk werkzaam als LEIFarts?**	☐ Brussel ☐ Vlaams-Brabant ☐ Oost-Vlaanderen ☐ Limburg ☐ Antwerpen ☐ Andere: ____ ☐ West-Vlaanderen
4	**Welk specialisme oefent u momenteel hoofdzakelijk uit?**	☐ huisartsgeneeskunde ☐ ander specialisme: ____
5	**Hoeveel ongeneeslijk zieke patiënten heeft u in de afgelopen 12 maanden als <u>behandelende arts</u> verzorgd aan hun levenseinde?**	*Vul aantal in* ____ patiënten (eventueel bij benadering)
6	**Maakt u deel uit van een palliatief team?**	☐ ja ☐ neen
7	**Hebt u <u>buiten de LEIF opleiding</u> nog andere bijscholing gehad inzake levenseindezorg sinds de uitoefening van uw beroep als arts?** *(onder bijscholingen verstaan we studiedagen, seminaries, stages, trainingen, postacademische vorming)*	☐ ja ☐ neen → ga naar vraag 9 (deel B)
8	**Welke bijscholingen inzake levenseindezorg hebt u sinds de uitoefening van uw beroep gevolgd?**	☐ seminaries: ____ keer (bij benadering) ☐ studiedagen: ____ keer (bij benadering) ☐ interuniversitaire postacademische vorming in de palliatieve zorg voor artsen ☐ trainingsweekend rond stervens- en rouwbegeleiding ☐ stage

B	**De volgende vragen gaan over uw activiteiten als LEIFarts in de afgelopen 12 maanden. Vul telkens het aantal patiënten in waarvoor u specifieke activiteiten als LEIFarts hebt uitgevoerd.**	
9	**Voor hoeveel patiënten werd u <u>tijdens de afgelopen 12 maanden</u> als LEIFarts gecontacteerd om op te treden als 2de of 3de arts bij een euthanasieverzoek?**	____ patiënten (= totaal aantal) **Indien 0 patiënten, ga naar vraag 10**
	a. Voor hoeveel van dit totaal aantal patiënten werd u door onderstaande instanties gecontacteerd?	Aantal
	De centrale telefoonlijn LEIFartsen/LEIFlijn	____ patiënten
	Behandelende arts	____ patiënten
	Patiënt zelf	____ patiënten
	Andere: ……	____ patiënten
	b. Bij hoeveel van dit totaal aantal patiënten bent u zelf niet opgetreden als 2de of 3de arts, maar hebt u doorverwezen naar een andere 2de of 3de (LEIF)arts (bv. omdat u niet beschikbaar was op dat moment, u zich niet onafhankelijk voelde tav de arts, enz.)	____ patiënten

c. Bij hoeveel patiënten voor wie u optrad als 2de of 3de arts was voldaan aan de voorwaarden voor euthanasie? ____ patiënten

Met de voorwaarden voor euthanasie wordt bedoeld dat het verzoek van de patiënt vrijwillig, overwogen en herhaald is, dat er aanhoudend fysiek of psychisch lijden is dat niet gelenigd kan worden en dat het gevolg is van een ernstige en ongeneeslijke aandoening. In dit onderzoek beschouwen we hulp bij zelfdoding ook als euthanasie indien aan dezelfde voorwaarden is voldaan.

Hoeveel kregen euthanasie? ____ patiënten

Bij hoeveel is de euthanasie niet doorgegaan? ____ patiënten

Van hoeveel kent u de afloop niet? ____ patiënten

d. Bij hoeveel van deze patiënten was u aanwezig bij de uitvoering van de euthanasie? ____ patiënten

Bij hoeveel van deze patiënten hebt u geholpen met de voorbereiding van de toediening? ____ patiënten

Bij hoeveel van deze patiënten hebt u de middelen zelf toegediend? ____ patiënten

10 Voor hoeveel patiënten hebt u tijdens de afgelopen 12 maanden, na consultatie met de patiënt, een medisch advies als LEIFarts gegeven over beslissingen aan het levenseinde met een mogelijk levensverkortend effect anders dan euthanasie?
bv. het stopzetten of niet starten van behandeling, opdrijven van pijnmedicatie, palliatieve sedatie, enz.

____ patiënten

Indien 0 patiënten, ga naar vraag 11

Bij hoeveel van dit totaal aantal patiënten besprak u de volgende medische beslissingen met de behandelende arts?

Niet-behandelingsbelissing (incl. stopzetten voeding) ____ patiënten

Continue diepe sedatie tot aan het overlijden ____ patiënten

Intensivering van pijn- of symptoombestrijding ____ patiënten

Levensbeëindigend handelen zonder dat de patiënt hierom nog kon verzoeken ____ patiënten

Andere:…… ____ patiënten

11 Aan hoeveel van onderstaande personen hebt u tijdens de afgelopen 12 maanden als LEIFarts uitsluitend informatie verstrekt inzake onderwerpen over het levenseinde, zonder een raadpleging te doen? Het gaat hierbij om individuele vragen (geen voordrachten of lezingen). Geef telkens bij benadering weer aan hoeveel artsen, patiënten of anderen u welke informatie gaf.

	artsen	patiënten/naasten van patiënten	anderen
Wettelijke procedure voor euthanasie			
Praktische uitvoering van euthanasie (middelen, methode)			
Het LEIF initiatief/de werking van LEIFartsen of LEIFnurses			
Palliatieve zorg			
Medische beslissingen anders dan euthanasie			
Wilsbeschikking/levenstestament			
Andere:			

12 Bij hoeveel patiënten werd u er in de afgelopen 12 maanden op het laatste moment bijgeroepen om te helpen met het toedienen van de middelen voor euthanasie, zonder dat u was opgetreden als 2de of 3de arts? ____ patiënten

C Volgende vragen hebben betrekking op de werking van LEIF

13 Geef aan in welke mate u het eens of oneens bent met de volgende stellingen

	helemaal oneens	eerder oneens	eens noch oneens	eerder eens	helemaal eens
a) De 1ste van 5 modules van de LEIF opleiding volgen is voldoende om als LEIFarts aan de slag te gaan	☐	☐	☐	☐	☐
b) Het bijkomend registreren van de LEIF raadplegingen ten behoeve van het LEIF secretariaat zou de kwaliteit van de raadplegingen ten goede komen	☐	☐	☐	☐	☐
c) In de LEIF opleiding wordt voldoende aandacht besteed aan • de juridische aspecten van euthanasie	☐	☐	☐	☐	☐
• medische beslissingen aan het levenseinde (andere dan euthanasie)	☐	☐	☐	☐	☐
• palliatieve zorg	☐	☐	☐	☐	☐
• de praktische/technische uitvoering van euthanasie	☐	☐	☐	☐	☐
• het ethisch/ levensbeschouwelijke kader van levens-eindebeslissingen	☐	☐	☐	☐	☐
• communicatievaardigheden als LEIFarts	☐	☐	☐	☐	☐

14 Vul in de onderstaande stellingen het volgens u gepaste aantal in

a) Per jaar zouden er ☐ intervisiebijeenkomsten van LEIF moeten zijn

b) ☐ consultatie(s) per jaar zijn volgens mij een minimum om de vaardigheden van LEIFarts op peil te houden

Op het einde van de vragenlijst is er ruimte voorzien om bovenstaande stellingen eventueel toe te lichten.

15 In Nederland worden de activiteiten van de vergelijkbare SCEN artsen al een aantal jaren geregistreerd. Deze gegevens worden gebruikt om de werking van de SCEN artsen in kaart te brengen. Op die manier kunnen de SCEN artsen zelf de kwaliteit van hun raadplegingen verbeteren. Met onderstaande vragen wil het LEIF secretariaat nagaan in hoeverre dit haalbaar is voor de LEIFartsen.

Bent u bereid uw raadplegingen als 2de of 3de arts bij euthanasie systematisch te registreren ten behoeve van het LEIF secretariaat?	☐ ja ☐ ja, op voorwaarde dat ☐ ☐ neen
→ Zo ja, op welke manier? (meerdere antwoorden mogelijk)	☐ op papier registreren na elke raadpleging ☐ elektronisch registreren na elke raadpleging ☐ een **overzicht** geven van mijn activiteiten om het half jaar op papier ☐ een **overzicht** geven van mijn activiteiten om het half jaar elektronisch ☐ anders: ☐
→ Zo neen, waarom niet? (meerdere antwoorden mogelijk)	☐ ik heb te weinig tijd ☐ het heeft geen nut ☐ het is teveel rompslomp ☐ dit is een zaak tussen de arts en de patiënt of tussen artsen onderling ☐ andere reden: ☐

D De volgende vragen gaan over UW LAATSTE OPTREDEN als verplichte 2de of 3de arts bij een euthanasieverzoek in de afgelopen 12 maanden. Indien u in de afgelopen 12 maanden niet bent opgetreden als 2de of 3de arts, ga dan naar vraag 33.

16 Op welke manier werd u in dit geval gecontacteerd?

- ☐ via de centrale telefoonlijn LEIFartsen/ LEIFlijn
- ☐ de arts contacteerde mij rechtstreeks (al dan niet telefonisch)
- ☐ op een andere wijze: _____

17 Was de arts die u contacteerde zelf een LEIFarts?

- ☐ ja
- ☐ neen

18 Wat was het specialisme van de behandelende arts?
(1 mogelijkheid aankruisen)

- ☐ huisartsgeneeskunde
- ☐ oncologie/ radiotherapie
- ☐ inwendige geneeskunde
- ☐ anesthesie
- ☐ neurologie
- ☐ chirurgie
- ☐ psychiatrie
- ☐ gastro-enterologie
- ☐ cardiologie
- ☐ spoedarts
- ☐ oftalmologie
- ☐ geriatrie
- ☐ pediatrie
- ☐ gynaecologie
- ☐ pneumologie
- ☐ keel-neus-oor heelkunde
- ☐ urologie
- ☐ radiologie
- ☐ ander specialisme: _____

19 Hoe zeker, denkt u, was de behandelende arts al van zijn besluit tijdens het eerste contact met u?
(maximum 1 mogelijkheid aankruisen)

- ☐ had al aan de patiënt toegezegd het verzoek in te willigen
- ☐ had al besloten het in te willigen maar nog niet aan de patiënt toegezegd
- ☐ wilde het waarschijnlijk inwilligen
- ☐ twijfelde nog over het al dan niet inwilligen
- ☐ wilde het waarschijnlijk niet inwilligen
- ☐ had besloten het niet in te willigen maar nog niet aan de patiënt gezegd
- ☐ had al aan de patiënt gezegd het verzoek niet in te willigen
- ☐ weet niet

20 Wat was het geslacht van de patiënt?

- ☐ vrouw
- ☐ man

21 Wat was de leeftijd van de patiënt?

- ☐ < 40 jaar
- ☐ 40 – 49 jaar
- ☐ 50 - 59 jaar
- ☐ 60 – 69 jaar
- ☐ 70 – 79 jaar
- ☐ 80 jaar of ouder

22 Wat was de hoofddiagnose van de patiënt?
(maximum 1 mogelijkheid aankruisen)

- ☐ longkanker
- ☐ dikke darmkanker
- ☐ prostaatkanker
- ☐ maagkanker
- ☐ borstkanker
- ☐ pancreaskanker
- ☐ andere kanker
- ☐ MS/ALS
- ☐ COPD
- ☐ AIDS
- ☐ CVA
- ☐ hartfalen
- ☐ (beginnende) dementie
- ☐ algehele achteruitgang
- ☐ psychiatrische aandoening, nl. _____
- ☐ andere, namelijk _____

23 Wat was/waren de reden(en) van de patiënt om zijn verzoek tot euthanasie te doen?
(meerdere antwoorden mogelijk)

- ☐ a. angst om te stikken
- ☐ b. ontluistering/verlies van waardigheid
- ☐ c. invaliditeit
- ☐ d. lijden zonder uitzicht op verbetering
- ☐ e. depressie
- ☐ f. afhankelijkheid
- ☐ g. pijn
- ☐ h. algehele zwakte/ moeheid
- ☐ i. levensmoeheid
- ☐ j. braken
- ☐ k. niet tot last willen zijn voor familie/omgeving
- ☐ l. benauwdheid
- ☐ m. anders: _____

24 Welke van de aangekruiste redenen was de meest belangrijke voor de patiënt?
(omcirkel de overeenstemmende letter)

a – b – c – d – e – f – g – h – i – j – k – l - m

25 **Heeft de patiënt het verzoek schriftelijk vastgelegd?**

- ☐ ja
- ☐ neen

26 **Wat was uw eindoordeel?**

- ☐ ik vond dat aan alle voorwaarden van de euthanasiewet was voldaan
- ☐ ik vond dat (nog) niet aan alle voorwaarden was voldaan, namelijk
  - ○ geen ondraaglijk lijden
  - ○ geen uitzichtloze toestand
  - ○ geen vrijwillig verzoek
  - ○ geen weloverwogen verzoek
  - ○ patiënt was niet wilsbekwaam
  - ○ andere behandelingsvormen waren onvoldoende uitgeprobeerd
  - ○ anders:
- ☐ ik heb geen eindoordeel gegeven

27 **Heeft de euthanasie uiteindelijk plaatsgehad?**

- ☐ ja
- ☐ neen
- ☐ weet niet

28 **Welke van de volgende werkzaamheden heeft u in het kader van deze consultatie uitgevoerd? Overloop de lijst zorgvuldig en kruis telkens aan indien u de handeling hebt uitgevoerd.**

- ☐ telefonisch gesprek met de behandelende arts
- ☐ face-to-face overleg met de behandelende arts
- ☐ inzage patiëntendossier
- ☐ gesprek met patiënt
- ☐ lichamelijk onderzoek van de patiënt
- ☐ gesprek met familie/naasten van de patiënt
- ☐ gesprek met zorgverlenend team
- ☐ vragen naar bijkomende mening van collega LEIFarts
- ☐ gesprek met een andere behandelende arts
- ☐ gesprek met iemand van het LEIF secretariaat
- ☐ raadplegen van literatuur
- ☐ aanwezig zijn bij de euthanasie
- ☐ praktische hulp bij het uitvoeren van de euthanasie
- ☐ zelf toedienen van de middelen
- ☐ opstellen schriftelijk verslag van de raadpleging
- ☐ hulp bij invullen van registratieformulier voor de Controlecommissie
- ☐ registratie voor het LEIF secretariaat
- ☐ anders:

29 **Hoeveel tijd heeft het afhandelen van de bovenstaande werkzaamheden u in totaal gekost?**
(hiermee bedoelen we al uw werkzaamheden en verplaatsingen inbegrepen)

uren

minuten

30 **Kunt u aangeven welk deel (%) van deze tijd u tijdens uw consultatiemomenten of erbuiten heeft geïnvesteerd in het afhandelen van de werkzaamheden voor dit euthanasieverzoek?**

% tijdens mijn consultatie-uren

% buiten mijn consultatie-uren

31 **Bent u vergoed voor uw consultatie als 2de of 3de arts?**

- ☐ ja, ik rekende euro aan
  - ○ op mijn initiatief
  - ○ op initiatief van de patiënt
  - ○ op initiatief van de behandelende arts
- ☐ neen

32 **Hebt u na het afronden van de consultatie nog contact gehad met de behandelende arts inzake het euthanasieverzoek en/of de raadpleging?**

- ☐ ja
- ☐ neen

33 Indien u nog opmerkingen heeft of verduidelijkingen bij uw antwoorden wil geven, kan u dat hier doen

Hartelijk dank voor uw medewerking! Indien u het laatste deel (D) hebt ingevuld, verzoeken wij u graag om de bruine enveloppe door te sturen naar de behandelende arts en om op de bijgevoegde brief de referentie (datum en plaats van consultatie) van de patiënt in kwestie te schrijven en deze brief in de bruine enveloppe te steken. Zo weet de arts om welke patiënt het gaat. De brief naar de behandelende arts hebben wij reeds voor u gefrankeerd.

nr:

A	**De volgende vragen gaan over uzelf**	
1	**U bent**	■ vrouw ■ man
2	**Wat is uw leeftijd?**	■ < 30 jaar ■ 40 - 49 jaar ■ 60 jaar of ouder ■ 30 - 39 jaar ■ 50 – 59 jaar
3	**In welke regio/provincie bent u hoofdzakelijk werkzaam als arts?**	☐ Brussel ☐ Vlaams-Brabant ☐ Oost-Vlaanderen ☐ Limburg ☐ Antwerpen ☐ Andere: ☐ West-Vlaanderen
4	**Hoeveel ongeneeslijk zieke patiënten heeft u in de afgelopen 12 maanden als behandelende arts verzorgd aan hun levenseinde?**	Vul aantal in patiënten *(eventueel bij benadering)*
5	**Hebt u eerder al eens een tweede arts geraadpleegd in het kader van een euthanasieverzoek?**	☐ neen ☐ ja, niet-LEIFarts(en) ☐ ja, LEIFarts(en) ☐ ja, beide
6	**Hebt u sinds de uitoefening van uw beroep bijscholing gevolgd inzake levenseindezorg?** *(onder bijscholingen verstaan we studiedagen, seminaries, stages, trainingen, postacademische vorming)*	■ ja ■ neen → ga naar vraag 8 (deel B)
7	**Welke bijscholingen inzake levenseindezorg hebt u sinds de uitoefening van uw beroep gevolgd?** *(meerdere antwoorden mogelijk)*	☐ seminaries: keer ☐ studiedagen: keer ☐ opleiding van de LEIFartsen ☐ interuniversitaire postacademische vorming in de palliatieve zorg voor artsen ☐ trainingsweekend rond stervens- en rouwbegeleiding ☐ stage
B	**De volgende vragen gaan over uw raadpleging met een LEIFarts in de afgelopen 12 maanden. In de begeleidende brief van de LEIFarts in kwestie kan u lezen om welke LEIFarts en patiënt het gaat.**	
8	**Op welke manier nam u contact op met de LEIFarts?**	■ via de centrale telefoonlijn LEIFartsen/LEIFlijn ■ rechtstreeks (al dan niet telefonisch) ■ op een andere wijze:
9	**Nam u contact op met deze arts net omdat het een LEIFarts is?**	■ ja ■ neen → ga naar vraag 11
10	**Wat was/waren voor u de reden(en) om voor het raadplegen van een 2de arts in dit geval een LEIFarts te vragen?** *(meerdere antwoorden mogelijk)*	☐ deskundigheid van LEIFartsen als tweede arts ☐ onafhankelijkheid van de tweede arts ☐ het ging om een complexe situatie ☐ bereikbaarheid/beschikbaarheid van de LEIFartsen ☐ vermijden belasting van andere collega's ☐ toetsing van het eigen oordeel

		☐ geen andere tweede arts bekend of bereikbaar	
		☐ vra(a)g(en) over en/of ondersteuning bij de juridische procedure	
		☐ vra(a)g(en) over de praktische uitvoering van euthanasie	
		☐ anders, nl:	
11	**Kende u de arts?**	☐ neen	■ ja, collega uit mijn ziekenhuis
	(meerdere antwoorden mogelijk)	■ ja, van naam	■ ja, al eens beroep op gedaan als LEIFarts
		■ ja, collega uit de regio	
		■ ja, praktijkgenoot	■ ja, bevriend collega
		■ ja, anders, nl.	

12 Kende de LEIFarts de patiënt?

- ☐ neen
- ☐ ja, als medebehandelaar
- ☐ ja, anders, nl.

13 Hoeveel tijd zat er tussen het eerste mondelinge verzoek van de patiënt en uw contactname met de LEIFarts?

- ■ minder dan een dag
- ■ 1 dag
- ■ 2 dagen
- ■ 3 – 5 dagen
- ■ 6 – 9 dagen
- ■ 10 – 14 dagen
- ■ 15 – 30 dagen
- ■ 31– 60 dagen
- ■ 2 maanden – 4 maanden
- ■ meer dan 4 maanden

14 Was de patiënt in staat om te communiceren op het moment dat u de LEIFarts contacteerde?

- ■ ja
- ■ neen
- ■ soms wel, soms niet
- ■ weet niet

15 Wat was de hoofddiagnose van de patiënt?

(1 mogelijkheid aankruisen)

- ■ longkanker
- ■ borstkanker
- ■ COPD
- ■ dikke darmkanker
- ■ pancreaskanker
- ■ AIDS
- ■ prostaatkanker
- ■ andere kanker
- ■ CVA
- ■ maagkanker
- ■ MS/ALS
- ■ hartfalen
- ■ (beginnende) dementie
- ■ algehele achteruitgang
- ■ psychiatrische aandoening, namelijk
- ■ andere, namelijk

16 Hoe stond u tegenover het verzoek om euthanasie toe te passen toen u de LEIFarts contacteerde?

- ■ ik had al aan de patiënt toegezegd het verzoek in te willigen
- ■ ik had al besloten het in te willigen maar nog niet aan de patiënt toegezegd
- ■ ik wilde het waarschijnlijk inwilligen
- ■ ik twijfelde nog over het al dan niet inwilligen
- ■ ik wilde het waarschijnlijk niet inwilligen
- ■ ik had besloten het niet in te willigen maar nog niet aan de patiënt gezegd
- ■ ik had al aan de patiënt gezegd dat ik het verzoek niet zou inwilligen
- ■ weet niet

17 Welke onderwerpen zijn aan de orde gekomen tijdens uw gesprek met de LEIFarts?

(meerdere antwoorden mogelijk)

- ☐ de ondraaglijkheid van het lijden
- ☐ de medisch uitzichtloze toestand
- ☐ de te verwachten termijn tot overlijden
- ☐ mogelijke alternatieve curatieve behandelingen
- ☐ mogelijke alternatieve palliatieve behandelingen
- ☐ de vrijwilligheid van het verzoek
- ☐ de weloverwogenheid van het verzoek
- ☐ de duurzaamheid (het herhaaldelijke) van het verzoek
- ☐ het tijdstip van uitvoering
- ☐ de toe te passen methode van levensbeëindiging, bv. welke middelen, op welke manier
- ☐ de vraag of het in deze situatie verantwoord was om euthanasie toe te passen
- ☐ de plaats van uitvoering
- ☐ de vraag of de LEIFarts zou willen assisteren bij de euthanasie
- ☐ de registratieprocedure/ het registratie formulier voor de controlecommissie
- ☐ juridische aspecten
- ☐ anders, nl:

18 Wat was het eindoordeel van de LEIFarts?

- ☐ vond dat aan alle voorwaarden van de euthanasiewet was voldaan
- ☐ vond dat (nog) niet aan alle voorwaarden was voldaan, namelijk
  - ● geen ondraaglijk lijden

- geen medisch uitzichtloze toestand
- geen vrijwillig verzoek
- geen weloverwogen verzoek
- patiënt was niet wilsbekwaam
- andere behandelingsvormen waren onvoldoende uitgeprobeerd
- anders:

■ heeft geen eindoordeel gegeven

19	**Heeft de LEIFarts zijn uiteindelijke oordeel schriftelijk vastgelegd?**	☐ ja ☐ neen ☐ weet niet
20	**In hoeverre heeft het oordeel van de LEIFarts meegespeeld in uw uiteindelijke besluitvorming?**	☐ in belangrijke mate ☐ nauwelijks ☐ enigszins ☐ niet
21	**Hebt u uiteindelijk euthanasie toegepast?**	☐ ja ☐ neen, ik heb het verzoek geweigerd → **ga naar vraag 23** ☐ neen, patiënt wenste geen euthanasie meer → **ga naar vraag 23** ☐ neen, patiënt overleed voor de uitvoering → **ga naar vraag 24** ☐ neen, een andere arts voerde de euthanasie uit
22	**Hebt u dit overlijden gemeld aan de Federale Controle – en Evaluatiecommissie?**	☐ ja → **ga naar vraag 24** ☐ neen → **ga naar vraag 24**
23	**Hebt u toen een andere medische beslissing met mogelijk levensverkortend effect genomen?** *(meerdere antwoorden mogelijk)*	☐ ja, een niet-behandelbeslissing (incl. stopzetten van vocht/voeding) ☐ ja, continue diepe sedatie tot aan het overlijden (al dan niet met toediening van vocht/voeding) ☐ ja, pijn – en/of symptoombestrijding met mogelijk levensverkortend effect ☐ ja, andere: ☐ neen, geen andere medische beslissing met mogelijk levensverkortend effect
24	**Hoeveel tijd zat er tussen het eerste contact met de LEIFarts en het overlijden van de patiënt?**	☐ minder dan een dag ☐ 1 dag ☐ 2 dagen ☐ 3 – 5 dagen ■ 6 – 9 dagen ■ 10 – 14 dagen ■ meer dan 2 weken
25	**Hebt u een verslag bijgehouden van uw besluitvorming?** *(meerdere antwoorden mogelijk)*	☐ Neen ☐ ja, korte aantekeningen in het dossier ☐ ja, afzonderlijk document ☐ ja, ingevulde lijst met aandachtspunten

C In het volgende deel krijgt u een aantal stellingen en vragen over uw ervaring van de raadpleging van deze LEIFarts

25	helemaal oneens	eerder oneens	eens noch oneens	eerder eens	helemaal eens	niet van toepassing	weet niet
Het LEIF secretariaat was makkelijk te bereiken	■	■	■	■	■	■	■
Ik kreeg voldoende snel een LEIFarts toegewezen door het LEIF secretariaat	■	■	■	■	■	■	■
De LEIFarts had voldoende kennis over de mogelijkheden van palliatieve zorg	■	■	■	■	■	■	■
De LEIFarts was in staat om de wilsbekwaamheid van de patiënt te beoordelen	■	■	■	■	■	■	■
De LEIFarts had voldoende kennis over ● de aandoening van de patiënt	■	■	■	■	■	■	■

	helemaal oneens	eerder oneens	eens noch oneens	eerder eens	helemaal eens	niet van toepassing	weet niet
• de juridische procedure	▪	▪	▪	▪	▪	▪	▪
• de uitvoering van euthanasie	▪	▪	▪	▪	▪	▪	▪
De LEIFarts had voldoende communicatievaardigheden							
in zijn/haar contact met mij	▪	▪	▪	▪	▪	▪	▪
in zijn/ haar contact met de patiënt (en familie)	▪	▪	▪	▪	▪	▪	▪
De werkzaamheden van de LEIFarts waren voldoende om een goed inzicht in de situatie te krijgen	▪	▪	▪	▪	▪	▪	▪
Het raadplegen van de LEIFarts was een belangrijke steun in het besluitvormingsproces	▪	▪	▪	▪	▪	▪	▪
De LEIFarts bleek tot een onafhankelijk oordeel in staat	▪	▪	▪	▪	▪	▪	▪
De kwaliteit van de raadpleging van de LEIFarts was over het algemeen goed	▪	▪	▪	▪	▪	▪	▪

27 Hebt u ook wel eens een LEIFarts gecontacteerd enkel voor informatie?

▪ neen

▪ ja, ____ keer *(vul aantal keer in)*

28 Voelt u zich ondersteund door het idee dat u voor een raadpleging van een 2de arts bij een euthanasieverzoek, beroep kan doen op een LEIFarts?

▪ in belangrijke mate

▪ enigszins

▪ nauwelijks

▪ niet

29 Welke suggesties tot verbetering zou u zelf nog voorstellen voor het LEIFartsen initiatief?

30 Indien u nog opmerkingen hebt, kan u die hier vermelden.

Hartelijk dank voor uw medewerking! In het pakket dat u ontving, zit een enveloppe waarmee u deze vragenlijst naar ons kan terugsturen. U hoeft deze niet te frankeren.

MELC
monitoring quality of end-of-life care

Houdingen en ervaringen van artsen omtrent beslissingen aan het levenseinde van patiënten

A. Specialisme en werkomgeving

1	Bent u momenteel werkzaam als arts?	☐ ja ☐ neen → *Einde van de vragenlijst. Gelieve deze enquête terug te sturen d.m.v. de bijgevoegde omslag.*
2	Sinds hoeveel jaren?	____ jaren
3	Maakt u momenteel deel uit van een palliatief team/palliatieve eenheid?	☐ ja ☐ neen
4	Hebt u ooit enige formele vorming genoten in de palliatieve zorg? *(meerdere antwoorden mogelijk)*	☐ neen ☐ ja, in de basis artsenopleiding ☐ ja, in de Interuniversitaire Postacademische Vorming in de Palliatieve Zorg voor artsen ☐ ja, in nascholingscursus(sen) ☐ ja, andere, nl.: ____
5	Hoeveel patiënten in terminale fase heeft u verzorgd gedurende de afgelopen 12 maanden?	____ patiënt(en)

B. Stellingen

6 Geef a.u.b. aan in hoeverre u het persoonlijk eens of oneens bent met de volgende stellingen.

		Helemaal oneens				Helemaal eens
		-2	-1	0	+1	+2
A. Stellingen over beslissingen aan het levenseinde bij patiënten						
I	Iedereen heeft het recht om zelf te beschikken over zijn of haar leven en dood.	☐	☐	☐	☐	☐
II	Het toedienen van levensbeëindigende middelen op expliciet verzoek van de patiënt is aanvaardbaar bij patiënten met een terminale ziekte met extreme, oncontroleerbare pijn of ander oncontroleerbaar lijden.	☐	☐	☐	☐	☐
III	Indien een ongeneeslijke zieke ondraaglijk lijdt en niet in staat is om zelf beslissingen te nemen, dan zou de arts (met het verzorgend team) moeten kunnen beslissen om levensbeëindigende middelen toe te dienen.	☐	☐	☐	☐	☐
IV	Ik ben in geen enkel geval bereid om op expliciet verzoek van de patiënt middelen toe te dienen om diens levenseinde te bespoedigen.	☐	☐	☐	☐	☐
V	Voldoende beschikbaarheid van palliatieve zorg voorkomt bijna alle verzoeken om levensbeëindiging.	☐	☐	☐	☐	☐
VI	Levensbeëindiging op verzoek van de patiënt kan deel uitmaken van goede zorg aan het levenseinde.	☐	☐	☐	☐	☐
VII	Ik ben eerder bereid om continue diepe sedatie toe te passen op verzoek van de patiënt dan tot het toedienen van levensbeëindigende middelen op verzoek van de patiënt.	☐	☐	☐	☐	☐
VIII	Indien nodig zou ik een patiënt middelen tegen pijn en lijden toedienen, zelfs indien deze middelen het levenseinde van de patiënt mogelijk bespoedigen.	☐	☐	☐	☐	☐
IX	In alle omstandigheden zouden artsen naar het behouden van het leven van hun patiënten moeten streven, zelfs indien patiënten vragen om hun levenseinde te versnellen.	☐	☐	☐	☐	☐

LET OP!
Het is belangrijk dat u bij het beantwoorden van de stellingen hierna gebruik maakt van de volgende definitie:
Euthanasie: het opzettelijk levensbeëindigend handelen op expliciet verzoek van de patiënt door de arts

B. Stellingen over de euthanasiewet						
X	Euthanasie zou wettelijk aanvaardbaar moeten zijn bij een minderjarige patiënt die in staat is tot een redelijke waardering van zijn of haar belangen.	☐	☐	☐	☐	☐
XI	Euthanasie zou wettelijk aanvaardbaar moeten zijn bij een wilsonbekwaam geworden patiënt (vb. door dementie, encefalopathie, hersenmetastasen) die in het bezit is van een geldige schriftelijke wilsverklaring voor euthanasie.	☐	☐	☐	☐	☐
XII	De euthanasiewet draagt bij tot de zorgvuldigheid van het medisch handelen aan het levenseinde door artsen.	☐	☐	☐	☐	☐

		Helemaal oneens				Helemaal eens
		-2	-1	0	+1	+2
XIII	De euthanasiewet verhindert de verdere uitbouw van de palliatieve zorg.	☐	☐	☐	☐	☐
XIV	Ik ben voldoende geïnformeerd over de inhoud van de euthanasiewet.	☐	☐	☐	☐	☐
C. Stellingen over de meldings-, controle-, en evaluatieprocedure voor euthanasie						
XV	Euthanasie is een zaak van de arts en de patiënt waar de Controle- en Evaluatiecommissie niet moet op toezien.	☐	☐	☐	☐	☐
XVI	Maatschappelijke controle op de euthanasiepraktijk is noodzakelijk.	☐	☐	☐	☐	☐
XVII	Het melden van euthanasie draagt bij tot de zorgvuldigheid van medisch handelen aan het levenseinde door artsen.	☐	☐	☐	☐	☐
D. Stellingen over het raadplegen van een tweede arts bij een euthanasieverzoek						
XVIII	Het raadplegen van een 2de arts is in elk geval van verzoek om euthanasie zinvol.	☐	☐	☐	☐	☐
XIX	Om een advies te kunnen geven als 2de arts bij een euthanasieverzoek zou men een speciale opleiding moeten hebben gekregen.	☐	☐	☐	☐	☐
XX	Het raadplegen van een collega arts draagt bij tot de zorgvuldigheid van medisch handelen aan het levenseinde door artsen.	☐	☐	☐	☐	☐

C. Vragen over LEIF

De volgende 5 vragen handelen over de LEIFartsen. LEIF staat voor LevensEinde Informatie Forum. LEIFartsen vormen een netwerk van artsen die vrijwillig een opleiding hebben gevolgd om advies te geven als 2de of 3de arts aan collega's die een euthanasieverzoek krijgen. Daarnaast geven zij ook informatie en advies aangaande levenseindebeslissingen

7	Was u voor het ontvangen van deze vragenlijst op de hoogte van het bestaan van het LEIF initiatief?	☐ ja ☐ neen → ***ga naar vraag 9***
8	Hebt u ooit al een LEIFarts geraadpleegd in het kader van een euthanasieverzoek van een van uw patiënten?	☐ ja, namelijk ☐ keer ☐ neen
9	Zou u in de toekomst, in situaties waarin dat van toepassing is, een LEIFarts raadplegen in het kader van een euthanasieverzoek van een van uw patiënten?	☐ ja ☐ neen
10	In welke mate voelt u zich ondersteund door de idee dat u voor een verplichte raadpleging van een 2de arts bij een euthanasieverzoek beroep kan doen op een LEIFarts?	☐ in belangrijke mate ☐ enigszins ☐ nauwelijks ☐ niet
11	In welke mate voelt u zich ondersteund door de idee dat u voor informatie en advies over vragen rond het levenseinde beroep kan doen op een LEIFarts?	☐ in belangrijke mate ☐ enigszins ☐ nauwelijks ☐ niet

D. Casussen

In dit deel van de vragenlijst worden u 5 hypothetische casussen voorgelegd. Ondanks het feit dat de casussen duidelijke reducties van de werkelijkheid zijn, u het gevoel kan hebben meer informatie over de patiënt nodig te hebben, of de casussen in uw praktijk niet of nauwelijks voorkomen, willen we u toch vragen om bij elke casus de vragen zo volledig mogelijk te beantwoorden.

Belangrijk: Bij alle casussen mag u ervan uitgaan dat er geen curatieve behandelopties meer voorhanden zijn en dat er voldoende palliatieve zorg beschikbaar is.

12. Casus 1

Patiënt is 73 jaar oud en heeft een inoperabel oesofaguscarcinoom met uitgebreide metastasering. Patiënt is vermoeid en heeft pijn in het hele lichaam. Patiënt heeft naar schatting nog enkele dagen te leven. Een morfinepomp geeft onvoldoende verlichting van de pijn. Patiënt heeft zijn arts meerdere malen expliciet verzocht om zijn leven te beëindigen. Besloten wordt om midazolam (vb. Dormicum®) te gaan toedienen tot het overlijden en geen vocht en voeding meer te geven. Patiënt geraakt al gauw in coma en overlijdt 3 dagen nadat met midazolam (vb. Dormicum®) werd gestart.

A	Kan u zich voorstellen dat u deze handelwijze daadwerkelijk in de praktijk zou toepassen?	☐ ja ☐ neen
B	Moet deze handelwijze volgens de huidige euthanasiewet gemeld worden aan de Federale Controle- en Evaluatiecommissie Euthanasie?	☐ ja ☐ neen ☐ weet niet

C	Stel dat u deze handelwijze had toegepast, zou u dit overlijden dan melden aan de Federale Controle- en Evaluatiecommissie Euthanasie?	☐ ja, want *(meerdere antwoorden mogelijk)* ☐ melden is in dit geval wettelijk verplicht ☐ ik zou verantwoording willen afleggen aan de maatschappij ☐ anders, nl.: ☐ neen, want *(meerdere antwoorden mogelijk)* ☐ melden is in dit geval niet wettelijk verplicht ☐ melden geeft te veel administratieve rompslomp ☐ melden geeft te veel risico's op juridische consequenties ☐ anders, nl.:
D	Welke term vindt u het beste passen bij de handelwijze die de arts toepast? *(slechts één optie aankruisen.)*	☐ palliatieve/terminale sedatie ☐ euthanasie ☐ levensbeëindigend handelen zonder uitdrukkelijk verzoek ☐ intensiveren van pijn- en symptoombestrijding ☐ anders, nl.:

13. Casus 2

Patiënt is 73 jaar oud en heeft een inoperabel oesofaguscarcinoom met uitgebreide metastasering. Patiënt is niet meer bij bewustzijn en kan niet meer communiceren, maar lijdt zichtbaar. Patiënt heeft naar schatting nog enkele dagen te leven. Het lijden van patiënt kan met een morfinepomp nauwelijks meer onder controle gehouden worden en de familie kan het lijden niet meer aanzien. Besloten wordt om morfine via een infuus te gaan toedienen. De dosis wordt om de 12 uur verdubbeld. Bovendien wordt valium aan het infuus toegevoegd. Patiënt overlijdt 24 uur nadat met het infuus is gestart.

A	Kan u zich voorstellen dat u deze handelwijze daadwerkelijk in de praktijk zou toepassen?	☐ ja ☐ neen
B	Moet deze handelwijze volgens de huidige euthanasiewet gemeld worden aan de Federale Controle- en Evaluatiecommissie Euthanasie?	☐ ja ☐ neen ☐ weet niet
C	Stel dat u deze handelwijze had toegepast, zou u dit overlijden dan melden aan de Federale Controle- en Evaluatiecommissie Euthanasie?	☐ ja, want *(meerdere antwoorden mogelijk)* ☐ melden is in dit geval wettelijk verplicht ☐ ik zou verantwoording willen afleggen aan de maatschappij ☐ anders, nl.: ☐ neen, want *(meerdere antwoorden mogelijk)* ☐ melden is in dit geval niet wettelijk verplicht ☐ melden geeft te veel administratieve rompslomp ☐ melden geeft te veel risico's op juridische consequenties ☐ anders, nl.:
D	Welke term vindt u het beste passen bij de handelwijze die de arts toepast? *(slechts één optie aankruisen.)*	☐ palliatieve/terminale sedatie ☐ euthanasie ☐ levensbeëindigend handelen zonder uitdrukkelijk verzoek ☐ intensiveren van pijn- en symptoombestrijding ☐ anders, nl.:

14. Casus 3

Patiënt is 73 jaar oud en heeft een inoperabel oesofaguscarcinoom met uitgebreide metastasering. Patiënt is vermoeid en heeft pijn in het hele lichaam. Patiënt heeft naar schatting nog enkele dagen te leven. Het lijden van patiënt kan met een morfinepomp niet meer onder controle gehouden worden. Patiënt heeft zijn arts meerdere malen expliciet verzocht om zijn leven te beëindigen. Op een afgesproken tijdstip dient de arts een slaapmiddel en vervolgens een spierverslapper toe. Patiënt overlijdt enkele minuten nadat de spierverslapper is toegediend.

A	Kan u zich voorstellen dat u deze handelwijze daadwerkelijk in de praktijk zou toepassen?	☐ ja ☐ neen
B	Moet deze handelwijze volgens de huidige euthanasiewet gemeld worden aan de Federale Controle- en Evaluatiecommissie Euthanasie?	☐ ja ☐ neen ☐ weet niet

C	Stel dat u deze handelwijze had toegepast, zou u dit overlijden dan melden aan de Federale Controle- en Evaluatiecommissie Euthanasie?	☐ ja, want *(meerdere antwoorden mogelijk)* ☐ melden is in dit geval wettelijk verplicht ☐ ik zou verantwoording willen afleggen aan de maatschappij ☐ anders, nl.: ☐ neen, want *(meerdere antwoorden mogelijk)* ☐ melden is in dit geval niet wettelijk verplicht ☐ melden geeft te veel administratieve rompslomp ☐ melden geeft te veel risico's op juridische consequenties ☐ anders, nl.:
D	Welke term vindt u het beste passen bij de handelwijze die de arts toepast? *(slechts één optie aankruisen.)*	☐ palliatieve/terminale sedatie ☐ euthanasie ☐ levensbeëindigend handelen zonder uitdrukkelijk verzoek ☐ intensiveren van pijn- en symptoombestrijding ☐ anders, nl.:

15. Casus 4

Patiënt is 73 jaar oud en heeft een inoperabel oesofaguscarcinoom met uitgebreide metastasering. Patiënt is vermoeid en heeft pijn in het hele lichaam. Patiënt heeft naar schatting nog enkele dagen te leven. De pijn van patiënt wordt behandeld met morfinepleisters, maar dit biedt onvoldoende verlichting. Patiënt heeft zijn arts meerdere malen expliciet verzocht om zijn leven te beëindigen. Besloten wordt om morfine via een pomp te gaan toedienen. De dosis wordt geleidelijk aan proportioneel verhoogd. Patiënt overlijdt 10 uur nadat met de morfinepomp is gestart.

A	Kan u zich voorstellen dat u deze handelwijze daadwerkelijk in de praktijk zou toepassen?	☐ ja ☐ neen
B	Moet deze handelwijze volgens de huidige euthanasiewet gemeld worden aan de Federale Controle- en Evaluatiecommissie Euthanasie?	☐ ja ☐ neen ☐ weet niet
C	Stel dat u deze handelwijze had toegepast, zou u dit overlijden dan melden aan de Federale Controle- en Evaluatiecommissie Euthanasie?	☐ ja, want *(meerdere antwoorden mogelijk)* ☐ melden is in dit geval wettelijk verplicht ☐ ik zou verantwoording willen afleggen aan de maatschappij ☐ anders, nl.: ☐ neen, want *(meerdere antwoorden mogelijk)* ☐ melden is in dit geval niet wettelijk verplicht ☐ melden geeft te veel administratieve rompslomp ☐ melden geeft te veel risico's op juridische consequenties ☐ anders, nl.:
D	Welke term vindt u het beste passen bij de handelwijze die de arts toepast? *(slechts één optie aankruisen.)*	☐ palliatieve/terminale sedatie ☐ euthanasie ☐ levensbeëindigend handelen zonder uitdrukkelijk verzoek ☐ intensiveren van pijn- en symptoombestrijding ☐ anders, nl.:

16. Casus 5

Patiënt is 73 jaar oud en heeft een inoperabel oesofaguscarcinoom met uitgebreide metastasering. Patiënt is vermoeid en heeft pijn in het hele lichaam. Patiënt heeft naar schatting nog enkele dagen te leven. Patiënt heeft zijn arts meerdere malen expliciet verzocht om zijn leven te beëindigen. Besloten wordt om morfine via een infuus te gaan toedienen. De dosis wordt om de 12 uur verdubbeld. Bovendien wordt valium aan het infuus toegevoegd. Patiënt overlijdt 24 uur nadat met het infuus is gestart.

A	Kan u zich voorstellen dat u deze handelwijze daadwerkelijk in de praktijk zou toepassen?	☐ ja ☐ neen
B	Moet deze handelwijze volgens de huidige euthanasiewet gemeld worden aan de Federale Controle- en Evaluatiecommissie Euthanasie?	☐ ja ☐ neen ☐ weet niet

C	Stel dat u deze handelwijze had toegepast, zou u dit overlijden dan melden aan de Federale Controle- en Evaluatiecommissie Euthanasie?	☐ ja, want *(meerdere antwoorden mogelijk)* ☐ melden is in dit geval wettelijk verplicht ☐ ik zou verantwoording willen afleggen aan de maatschappij ☐ anders, nl.: ☐ neen, want *(meerdere antwoorden mogelijk)* ☐ melden is in dit geval niet wettelijk verplicht ☐ melden geeft te veel administratieve rompslomp ☐ melden geeft te veel risico's op juridische consequenties ☐ anders, nl.:
D	Welke term vindt u het beste passen bij de handelwijze die de arts toepast? *(slechts één optie aankruisen.)*	☐ palliatieve/terminale sedatie ☐ euthanasie ☐ levensbeëindigend handelen zonder uitdrukkelijk verzoek ☐ intensiveren van pijn- en symptoombestrijding ☐ anders, nl.:

E. Euthanasieverzoeken

LET OP! Het is belangrijk dat u bij de beantwoording van onderstaande vragen steeds gebruik maakt van de volgende definitie: *Euthanasie: het opzettelijk levensbeëindigend handelen op expliciet verzoek van de patiënt door de arts*

17	Hebt u ooit een euthanasieverzoek van een patiënt gekregen?	☐ ja ☐ neen → ***Ga naar vraag 51***
18	Hebt u tijdens de afgelopen 24 maanden een euthanasieverzoek gekregen?	☐ ja, van ☐ patiënten (bij benadering) ☐ neen, niet tijdens de afgelopen 24 maanden, maar wel daarvoor → ***Ga naar vraag 22***
19	Bij hoeveel van deze patiënten hebt u een collega arts geraadpleegd voor advies in het kader van de euthanasiewet?	☐ patiënten
20	Bij hoeveel van deze patiënten werd ook daadwerkelijk euthanasie uitgevoerd?	☐ patiënten → ***Indien 0, ga naar vraag 22***
21	Bij hoeveel van deze patiënten hebt u de euthanasie gemeld bij de Federale Controle- en Evaluatiecommissie Euthanasie?	☐ patiënten

F. Meest recente euthanasieverzoek

In de volgende vragen peilen we naar uw ervaring met een concreet geval in de praktijk, namelijk het meest recente expliciete euthanasieverzoek dat u kreeg van 1 van uw patiënten.

22	In welk jaar hebt u het meest recente euthanasieverzoek gekregen van een patiënt?	
23	Wat was het geslacht van deze patiënt?	☐ vrouw ☐ man
24	Wat was de leeftijd van de patiënt?	☐ < 40 jaar ☐ 40 – 49 jaar ☐ 50 – 59 jaar ☐ 60 – 69 jaar ☐ 70 – 79 jaar ☐ 80 jaar of ouder
25	Wat was de hoofddiagnose van de patiënt? *(slechts één optie aankruisen)*	☐ kanker ☐ COPD ☐ AIDS ☐ CVA ☐ MS/ALS ☐ hartfalen ☐ (beginnende) dementie ☐ algehele achteruitgang ☐ psychiatrische aandoening, nl. ☐ andere, nl.

26	Wat was/waren de reden(en) van de patiënt om zijn of haar verzoek te doen? *(meerdere antwoorden mogelijk)*	☐ a. angst om te stikken ☐ b. ontluistering/verlies van waardigheid ☐ c. invaliditeit ☐ d. lijden zonder uitzicht op verbetering ☐ e. depressie ☐ f. afhankelijkheid ☐ g. pijn ☐ h. algehele zwakte/ moeheid ☐ i. levensmoeheid ☐ j. braken ☐ k. niet tot last willen zijn voor familie/omgeving ☐ l. benauwdheid ☐ m. andere:
27	Welke van de aangekruiste redenen was de belangrijkste voor de patiënt? *(omcirkel de overeenstemmende letter)*	a – b – c – d – e – f – g – h – i – j – k – l – m
28	Heeft de patiënt het verzoek schriftelijk vastgelegd?	☐ ja ☐ neen
29	Hoe stond u tegenover het verzoek?	☐ ik had al aan de patiënt toegezegd het verzoek in te willigen op het moment van het verzoek ☐ ik had al besloten het in te willigen maar nog niet aan de patiënt toegezegd ☐ ik wilde het waarschijnlijk inwilligen ☐ ik twijfelde nog over het al dan niet inwilligen ☐ ik wilde het waarschijnlijk niet inwilligen ☐ ik had besloten het niet in te willigen maar nog niet aan de patiënt gezegd ☐ ik had al aan de patiënt gezegd dat ik het verzoek niet zou inwilligen ☐ weet niet
30	Hebt u een collega (2de) arts geraadpleegd voor advies?	☐ ja ☐ neen → ***ga naar vraag 38***
31	Kende u deze arts? *(meerdere antwoorden mogelijk)*	☐ neen ☐ ja, enkel van naam ☐ ja, collega uit de regio ☐ ja, praktijkgenoot ☐ ja, collega uit mijn ziekenhuis ☐ ja, al eens beroep op gedaan ☐ ja, bevriend collega ☐ ja, anders, nl.
32	Kende deze arts de patiënt?	☐ neen ☐ ja, als medebehandelaar ☐ ja, op andere manier, nl:
33	Wat was het specialisme van deze arts?	☐ huisartsengeneeskunde ☐ ander specialisme:
34	Was deze 2de arts een LEIFarts?	☐ ja ☐ neen ☐ weet niet
35	Voerde de 2de arts volgende werkzaamheden uit?	

	ja	neen	weet niet
overleg met u	☐	☐	☐
inzage patiëntendossier	☐	☐	☐
gesprek met patiënt	☐	☐	☐
lichamelijk onderzoek van de patiënt	☐	☐	☐
gesprek met familie/naasten van de patiënt	☐	☐	☐
gesprek met zorgverlenend team	☐	☐	☐
gesprek met een andere behandelende arts (specialist, huisarts)	☐	☐	☐
bijkomend advies vragen van een 3de arts	☐	☐	☐
aanwezig zijn bij de levensbeëindiging	☐	☐	☐
praktische hulp bij het uitvoeren van de levensbeëindiging	☐	☐	☐
opstellen schriftelijk verslag van de raadpleging	☐	☐	☐
hulp bij invullen van registratieformulier voor de Federale Controlecommissie	☐	☐	☐
anders:			

36	Wat was het advies van de 2de arts? *(meerdere antwoorden mogelijk)*	☐ vond dat aan alle voorwaarden van de euthanasiewet was voldaan ☐ vond dat (nog) niet aan alle voorwaarden was voldaan, namelijk ✷ geen ondraaglijk lijden ✷ geen medisch uitzichtloze toestand ✷ geen vrijwillig verzoek ✷ geen weloverwogen verzoek ✷ patiënt was niet wilsbekwaam ✷ er waren nog palliatieve mogelijkheden ✷ anders ☐ heeft geen advies gegeven
37	In hoeverre heeft het advies van uw collega arts meegespeeld in uw uiteindelijke besluitvorming?	☐ in belangrijke mate ☐ enigszins ☐ nauwelijks ☐ niet
38	Hebt u verslag bijgehouden van uw besluitvorming?	☐ ja ☐ neen
39	Werd er uiteindelijk euthanasie toegepast?	☐ ja, door mezelf ☐ ja, maar een andere arts voerde de euthanasie uit ☐ neen, ik heb het verzoek geweigerd → ***ga naar vraag 41*** ☐ neen, patiënt wenste geen euthanasie meer → ***ga naar 41*** ☐ neen, patiënt overleed voor de uitvoering → ***ga naar vraag 42*** ☐ neen, patiënt leeft nog → ***ga naar vraag 42***
40	Hebt u dit overlijden gemeld aan de Federale Controle – en Evaluatiecommissie Euthanasie?	☐ ja → ***ga naar vraag 44*** ☐ neen → ***ga naar vraag 42***
41	Werd een andere medische beslissing met mogelijk levensverkortend effect genomen? *(meerdere antwoorden mogelijk)*	☐ ja, een niet- behandelingsbeslissing (incl. stopzetten vocht en voeding) ☐ ja, opdrijven van pijn- en symptoombestrijding met mogelijk levensverkortend effect ☐ ja, continue diepe sedatie tot aan het overlijden met mogelijk levensverkortend effect (al dan niet met toediening van vocht/voeding) ☐ ja, andere: ☐ neen, geen andere medische beslissing met mogelijk levensverkortend effect

G. Melden van euthanasie

42	Hebt u ooit al eens een geval van euthanasie gemeld bij de Federale Controle- en Evaluatiecommissie Euthanasie?	☐ nee, ik heb **nog nooit** euthanasie toegepast → ***ga naar vraag 51*** ☐ nee, ik heb wel **ooit** euthanasie toegepast, maar dit **nooit gemeld** → ***ga naar vraag 48*** ☐ ja
43	In welk jaar was het meest recente geval van euthanasie dat u gemeld heeft?	
44	Hebt u bij de melding aan de Commissie gebruik gemaakt van het standaard registratiedocument?	☐ ja, en ik heb het verkregen: ☐ via Internet ☐ via een collega ☐ via een LEIFarts ☐ via de medisch- ethische commissie van mijn instelling ☐ anders, nl: ☐ neen
45	Hoe heeft u de melding in zijn geheel ervaren? *(meerdere antwoorden mogelijk)*	☐ belastend ☐ ondersteunend ☐ tijdrovend ☐ opluchtend ☐ beschuldigend ☐ neutraal ☐ inbreuk op privacy ☐ anders, nl
46	Indien u iets zou kunnen veranderen aan de meldingsprocedure voor euthanasie wat zou u dan precies veranderen?	

47	Hebt u ooit wel eens een geval van euthanasie niet gemeld sinds de inwerkingtreding van de euthanasiewet?	☐ neen, ik heb wel al euthanasie toegepast, maar heb dit steeds gemeld → ***ga naar vraag 50*** ☐ ja
48	In welk jaar was het meest recente geval van euthanasie dat u niet gemeld heeft bij de Federale Controle- en Evaluatiecommissie Euthanasie?	
49	Wat was/waren de redenen om dit geval niet te melden? *(meerdere antwoorden mogelijk)*	☐ melden geeft te veel rompslomp ☐ euthanasie is een zaak tussen arts en patiënt ☐ er was mogelijk niet aan alle zorgvuldigheidsvoorwaarden voldaan ☐ vanwege mogelijke juridische consequenties ☐ andere reden, nl.
50	Is het denkbaar dat u in de toekomst een geval van euthanasie niet meldt?	☐ neen ☐ ja, indien:

H. Achtergrondgegevens

51	Wat is uw geslacht?	☐ vrouw ☐ man
52	Wat is uw leeftijd?	jaar
53	Wat beschouwt u als uw religie of levensovertuiging?	☐ rooms-katholiek ☐ andere religie / levensbeschouwing, nl. : ☐ protestants ☐ gelovig, doch geen specifieke religie ☐ vrijzinnig ☐ niet religieus
54	Gelegenheden als huwelijk, begrafenis en doop niet meegerekend, hoe vaak woont u dan een kerk- of religieuze dienst bij?	☐ meer dan eens per week ☐ een keer per jaar ☐ eens per week ☐ minder dan een keer per jaar ☐ eens per maand ☐ nooit, praktisch nooit ☐ alleen met Kerstmis/Pasen of andere bijzondere kerkelijke feestdagen

I. Tot slot

Wanneer uw beantwoording van de vragen naar uw oordeel nog verduidelijking behoeft wordt u vriendelijk verzocht die hier te geven:

EINDE

Hartelijk dank voor uw medewerking. Gelieve de vragenlijst naar ons terugsturen in de bijgevoegde enveloppe (frankeren niet nodig).

MELC
monitoring quality of end-of-life care

Attitudes et expériences de médecins concernant les décisions en fin de vie de patients

A. Spécialité et expérience

1	Etes-vous actuellement actif en tant que médecin?	☐ oui ☐ non → *fin du questionnaire. Veuillez renvoyer ce questionnaire en utilisant l'enveloppe jointe.*
2	Depuis combien d'années?	☐ années
3	Faites-vous actuellement partie d'une équipe/unité palliative ?	☐ oui ☐ non
4	Avez- vous déjà reçu une formation formelle en soins palliatifs? *(une ou plusieurs réponses possibles)*	☐ non ☐ oui, dans la formation de base des médecins ☐ oui, pendant une ou plusieurs journée(s) d'étude ☐ oui, dans une formation complémentaire de courte durée (< 40 heures) ☐ oui, dans une formation complémentaire de longue durée (> 40 heures) ☐ oui, autre, à savoir
5	Combien de patients en phase terminale avez-vous soigné au cours des 12 derniers mois?	☐ patiënt(en)

B. Positions

6 Veuillez indiquer svp dans quelle mesure vous êtes personnellement d'accord avec les propositions suivantes.

		Entièrement en désaccord -2	-1	0	+1	Entièrement d'accord +2
A. Positions sur les décisions relatives à la fin de vie des patients						
I	Chacun a le droit de disposer de sa vie et de sa mort.	☐	☐	☐	☐	☐
II	L'usage de médicaments qui terminent la vie sur demande explicite du patient est acceptable chez des patients atteint d'une maladie terminale accompagnée d'une douleur extrême et incontrôlable ou autre souffrance incontrôlable.	☐	☐	☐	☐	☐
III	Si un malade incurable souffre d'une façon insupportable et qu'il n'est pas en mesure de prendre des décisions lui-même, il faudrait permettre au médecin (avec l'équipe soignante) d'administrer des médicaments qui mettent fin à la vie.	☐	☐	☐	☐	☐
IV	Je ne suis en aucun cas disposé à administrer, sur demande du patient, des médicaments pour accélérer sa fin de vie.	☐	☐	☐	☐	☐
V	Une disponibilité suffisante de soins palliatifs prévient presque toutes les demandes de mettre fin à la vie.	☐	☐	☐	☐	☐
VI	Mettre fin à la vie sur demande du patient peut faire partie de la bonne pratique médicale en fin de vie.	☐	☐	☐	☐	☐
VII	Je suis disposé à pratiquer une sédation profonde et continue sur demande du patient, plutôt que d'administrer des médicaments qui mettent fin à la vie sur demande du patient.	☐	☐	☐	☐	☐
VIII	Si nécessaire, j'administrerai des médicaments contre la douleur et la souffrance à un patient, même si ces médicaments peuvent potentiellement accélérer la fin de vie du patient.	☐	☐	☐	☐	☐
IX	En toutes circonstances, les médecins devraient viser à préserver la vie de leurs patients, même si des patients demandent à accélérer leur fin de vie.	☐	☐	☐	☐	☐
ATTENTION ! ***Il est important que vous fassiez usage de la définition suivante en répondant aux positions ci-dessous :*** ***Euthanasie : mettre intentionnellement fin à la vie sur demande explicite du patient par le médecin***						
B. Positions sur la loi relative à l'euthanasie						
X	L'euthanasie devrait être légalement acceptable chez un patient mineur qui est capable de juger raisonnablement de ces intérêts.	☐	☐	☐	☐	☐
XI	L'euthanasie devrait être légalement acceptée pour un patient qui est dans l'incapacité cognitive de formuler sa demande (par exemple suite à une démence, une encéphalopathie, des métastases cervicales) si celui-ci est en possession d'une déclaration d'euthanasie valable.	☐	☐	☐	☐	☐
XII	La loi relative à l'euthanasie contribue aux soins relatifs à la fin de vie dispensés par des médecins.	☐	☐	☐	☐	☐

		Entièrement en désaccord				Entièrement d'accord
		-2	-1	0	+1	+2
XIII	La loi relative à l'euthanasie est un obstacle au développement des soins palliatifs.	☐	☐	☐	☐	☐
XIV	Je suis suffisamment informé sur le contenu de la loi relative à l'euthanasie.	☐	☐	☐	☐	☐
C. Positions sur la procédure de déclaration, de contrôle et d'évaluation concernant l'euthanasie						
XV	L'euthanasie est l'affaire du médecin et du patient dans laquelle la Commission Fédérale de Contrôle et d'Evaluation n'a pas à intervenir.	☐	☐	☐	☐	☐
XVI	Le contrôle social de la pratique de l'euthanasie est nécessaire.	☐	☐	☐	☐	☐
XVII	La déclaration de l'euthanasie contribue aux soins relatifs à la fin de vie par les médecins.	☐	☐	☐	☐	☐
D. Positions sur la consultation d'un second médecin chez une demande d'euthanasie						
XVIII	La consultation d'un second médecin est utile dans tous les cas de demande d'euthanasie.	☐	☐	☐	☐	☐
XIX	Pour pouvoir donner un avis en tant que 2ième médecin lors d'une demande d'euthanasie, on devrait avoir reçu une formation spéciale.	☐	☐	☐	☐	☐
XX	La consultation d'un collègue-médecin contribue aux soins relatifs à la fin de vie dispensés par les médecins.	☐	☐	☐	☐	☐

C. Cas

Dans cette partie du questionnaire, 5 cas hypothétiques vous sont présentés. Il est possible que ces cas ne se présentent pas ou presque pas dans votre cabinet ou que vous ayez le sentiment d'avoir besoin de plus d'information sur les patients. Même si les cas sont manifestement des réductions de la réalité, nous vous demandons néanmoins de répondre aux questions le plus complètement possible.

Important: dans tous les cas, vous pouvez partir du principe qu'il n'y a plus d'options de traitement curatifs disponibles, mais bien des soins palliatifs.

7. Cas 1

Le patient est âgé de 73 ans et a un carcinome de l'œsophage inopérable avec métastases étendues. Le patient est fatigué et a mal dans tout le corps. Les prévisions sont que le patient n'a plus que quelques jours à vivre. Une pompe à morphine soulage sa douleur insuffisamment. Le patient a demandé plusieurs fois et de façon explicite à son médecin de mettre fin à sa vie. La décision est prise d'administrer du midazolam (ex. Dormicum®) jusqu'au décès et de cesser l'hydratation et l'alimentation artificielle.
Le patient se retrouve rapidement dans un coma et décède 3 jours après le début de la prise de midazolam (ex. Dormicum®).

A	Pouvez-vous imaginer pratiquer cette procédure vous-même?	☐ oui ☐ non
B	Est-ce que cette procédure devrait être déclaré à la Commission Fédérale de Contrôle et d'Evaluation de l'Euthanasie ?	☐ oui ☐ non ☐ je ne sais pas
C	En supposant que vous ayez pratiqué cette procédure, déclareriez-vous ce décès à la Commission Fédérale de Contrôle et d'Evaluation?	☐ oui, parce que *(plusieurs réponses possibles)* ☐ la déclaration est obligatoire dans ce cas ☐ je voudrais le justifier à la société ☐ autre: ☐ non, parce que *(plusieurs réponses possibles)* ☐ la déclaration n'est pas obligatoire dans ce cas ☐ la déclaration implique trop de tracasseries administratifs ☐ la déclaration implique trop de risques de conséquences juridiques ☐ autre:
D	Quel est le terme qui convient le mieux selon vous au procédé pratiqué par le médecin? *(cochez seulement 1 option svp)*	☐ sédation palliative/terminale ☐ euthanasie ☐ actes de fin de vie sans demande explicite ☐ intensification du traitement contre la douleur et les symptômes ☐ autre:

8. Cas 2

Le patient est âgé de 73 ans et a un carcinome de l'œsophage inopérable avec métastases étendues. Le patient n'est plus conscient et ne peut plus communiquer, mais souffre visiblement. Les prévisions sont que le patient n'a plus que quelques jours à vivre. La souffrance du patient peut à peine être maitrisée par une pompe à morphine et la famille ne peut plus supporter cette souffrance. On décide d'administrer de la morphine par perfusion. La dose est doublée toutes les 12 heures. De plus, du valium est ajouté à la perfusion. Le patient décède 24 heures après que l'on a commencé la perfusion.

A	Pouvez-vous imaginer pratiquer cette procédure vous-même?	☐ oui ☐ non
B	Est-ce que cette procédure devrait être déclaré à la Commission Fédérale de Contrôle et d'Evaluation de l'Euthanasie ?	☐ oui ☐ non ☐ je ne sais pas
C	En supposant que vous ayez pratiqué cette procédure, déclareriez-vous ce décès à la Commission Fédérale de Contrôle et d'Evaluation?	☐ oui, parce que *(plusieurs réponses possibles)* ☐ la déclaration est obligatoire dans ce cas ☐ je voudrais le justifier à la société ☐ autre: ☐ non, parce que *(plusieurs réponses possibles)* ☐ la déclaration n'est pas obligatoire dans ce cas ☐ la déclaration implique trop de tracasseries administratifs ☐ la déclaration implique trop de risques de conséquences juridiques ☐ autre:
D	Quel est le terme qui convient le mieux selon vous au procédé pratiqué par le médecin? *(cochez seulement 1 option svp)*	☐ sédation palliative/terminale ☐ euthanasie ☐ actes de fin de vie sans demande explicite ☐ intensification du traitement contre la douleur et les symptômes ☐ autre:

9. Cas 3

Le patient est âgé de 73 ans et a un carcinome de l'œsophage inopérable avec métastases étendues. Le patient est fatigué et a mal dans tout le corps. Les prévisions sont que le patient n'a plus que quelques jours à vivre. Sa souffrance ne peut pas être maitrisée par une pompe à morphine. Le patient a demandé plusieurs fois de façon explicite à son médecin de mettre fin à sa vie. A un moment convenu, le médecin administre successivement un somnifère et un myorelaxant. Le patient décède quelques minutes après que le myorelaxant a été administré.

A	Pouvez-vous imaginer pratiquer cette procédure vous-même?	☐ oui ☐ non
B	Est-ce que cette procédure devrait être déclaré à la Commission Fédérale de Contrôle et d'Evaluation de l'Euthanasie ?	☐ oui ☐ non ☐ je ne sais pas
C	En supposant que vous ayez pratiqué cette procédure, déclareriez-vous ce décès à la Commission Fédérale de Contrôle et d'Evaluation?	☐ oui, parce que *(plusieurs réponses possibles)* ☐ la déclaration est obligatoire dans ce cas ☐ je voudrais le justifier à la société ☐ autre: ☐ non, parce que *(plusieurs réponses possibles)* ☐ la déclaration n'est pas obligatoire dans ce cas ☐ la déclaration implique trop de tracasseries administratifs ☐ la déclaration implique trop de risques de conséquences juridiques ☐ autre:
D	Quel est le terme qui convient le mieux selon vous au procédé pratiqué par le médecin? *(cochez seulement 1 option svp)*	☐ sédation palliative/terminale ☐ euthanasie ☐ actes de fin de vie sans demande explicite ☐ intensification du traitement contre la douleur et les symptômes ☐ autre:

10. Cas 4

Le patient est âgé de 73 ans et a un carcinome de l'œsophage inopérable avec métastases étendues. Le patient est fatigué et a mal dans tout le corps. Les prévisions sont que le patient n'a plus que quelques jours à vivre. Sa douleur est traitée avec un patch de morphine mais cela n'offre pas assez de soulagement. Le patient a demandé plusieurs fois de façon explicite à son médecin de mettre fin à sa vie. On décide d'administrer la morphine par pompe. La dose est augmentée progressivement et proportionnellement. Le patient décède 10 heures après avoir commencé à utiliser la pompe à morphine.

A	Pouvez-vous imaginer pratiquer cette procédure vous-même?	☐ oui ☐ non
B	Est-ce que cette procédure devrait être déclaré à la Commission Fédérale de Contrôle et d'Evaluation de l'Euthanasie ?	☐ oui ☐ non ☐ je ne sais pas
C	En supposant que vous ayez pratiqué cette procédure, déclareriez-vous ce décès à la Commission Fédérale de Contrôle et d'Evaluation?	☐ oui, parce que *(plusieurs réponses possibles)* ☐ la déclaration est obligatoire dans ce cas ☐ je voudrais le justifier à la société ☐ autre: ☐ non, parce que *(plusieurs réponses possibles)* ☐ la déclaration n'est pas obligatoire dans ce cas ☐ la déclaration implique trop de tracasseries administratifs ☐ la déclaration implique trop de risques de conséquences juridiques ☐ autre:
D	Quel est le terme qui convient le mieux selon vous au procédé pratiqué par le médecin? *(cochez seulement 1 option svp)*	☐ sédation palliative/terminale ☐ euthanasie ☐ actes de fin de vie sans demande explicite ☐ intensification du traitement contre la douleur et les symptômes ☐ autre:

11. Cas 5

Le patient est âgé de 73 ans et a un carcinome de l'œsophage inopérable avec métastases étendues. Le patient est fatigué et a mal dans tout le corps. Les prévisions sont que le patient n'a plus que quelques jours à vivre. Le patient a demandé plusieurs fois de façon explicite à son médecin de mettre fin à sa vie. On décide d'administrer de la morphine par perfusion. La dose est doublée toute les 12 heures. De plus, du valium est ajouté à la perfusion. Le patient décède 24 heures après avoir commencé avec la perfusion.

A	Pouvez-vous imaginer pratiquer cette procédure vous-même?	☐ oui ☐ non
B	Est-ce que cette procédure devrait être déclaré à la Commission Fédérale de Contrôle et d'Evaluation de l'Euthanasie ?	☐ oui ☐ non ☐ je ne sais pas
C	En supposant que vous ayez pratiqué cette procédure, déclareriez-vous ce décès à la Commission Fédérale de Contrôle et d'Evaluation?	☐ oui, parce que *(plusieurs réponses possibles)* ☐ la déclaration est obligatoire dans ce cas ☐ je voudrais le justifier à la société ☐ autre: ☐ non, parce que *(plusieurs réponses possibles)* ☐ la déclaration n'est pas obligatoire dans ce cas ☐ la déclaration implique trop de tracasseries administratifs ☐ la déclaration implique trop de risques de conséquences juridiques ☐ autre:
D	Quel est le terme qui convient le mieux selon vous au procédé pratiqué par le médecin? *(cochez seulement 1 option svp)*	☐ sédation palliative/terminale ☐ euthanasie ☐ actes de fin de vie sans demande explicite ☐ intensification du traitement contre la douleur et les symptômes ☐ autre:

D. Demandes d'euthanasie

ATTENTION ! Il est important que vous fassiez usage de la définition suivante dans la réponse des propositions ci-dessous: *Euthanasie: mettre intentionnellement fin à la vie sur demande explicite du patient par le médecin*

12	Avez-vous déjà reçu une demande d'euthanasie de la part d'un patient?	☐ oui ☐ non → ***passez à la question 45***
13	Avez-vous reçu une demande d'euthanasie au cours des 24 derniers mois?	☐ oui, de ____ patients (approximativement) ☐ non, pas durant les 24 derniers mois, mais avant → ***passez à la question 17***
14	Pour combien de ces patients avez-vous sollicité l'avis d'un confrère dans le cadre de la loi relative à l'euthanasie ?	____ patients
15	Pour combien de ces patients l'euthanasie a-t-elle effectivement été effectuée?	____ patients → ***Si 0, passez à la question 17***
16	Pour combien de ces patients avez-vous déclaré l'euthanasie à la Commission Fédérale de Contrôle et d'Evaluation d'Euthanasie ?	____ patients

E. Demande d'euthanasie la plus récente

Dans les questions suivantes nous enquêtons sur votre expérience sur un cas concret dans la pratique, c'est-à-dire la demande d'euthanasie explicite la plus récente d'un de vos patients.

17	En quelle année avez-vous reçu la demande d'euthanasie la plus récente d'un patient?	____
18	De quel sexe était le patient?	☐ féminin ☐ masculin
19	Quel âge avait le patient?	☐ < 40 ans ☐ 40 – 49 ans ☐ 50 – 59 ans ☐ 60 – 69 ans ☐ 70 – 79 ans ☐ 80 ans ou plus
20	Quel était le diagnostic principal du patient? *(cochez maximum 1 possibilité)*	☐ cancer ☐ BPCO ☐ SIDA ☐ AVC ☐ MS/SLA ☐ décompensation cardiaque ☐ démence (débutante) ☐ déclin général ☐ affection psychiatrique, à savoir ____ ☐ autre: ____
21	Quelle(s) était/étaient la/les raison(s) du patient pour faire cette demande? *(plusieurs réponses possibles)*	☐ a. peur d'étouffer ☐ b. perte de dignité ☐ c. invalidité ☐ d. souffrance sans perspective d'amélioration ☐ e. dépression ☐ f. dépendance ☐ g. douleur ☐ h. faiblesse/fatigue générale ☐ i. dégout de la vie ☐ j. vomissements ☐ k. ne (plus) vouloir être à charge de la famille/entourage ☐ l. essoufflement ☐ m. autre: ____
22	Laquelle des raisons cochées était la plus importante pour le patient? *(encerclez la lettre correspondante)*	a – b – c – d – e – f – g – h – i – j – k – l – m
23	Le patient a-t-il écrit sa demande d'euthanasie?	☐ oui ☐ non

24	Quelle était votre position à l'égard de cette demande?	☐ j'avais déjà promis au patient que j'allais consentir à sa demande au moment de celle-ci ☐ j'avais déjà décidé de consentir mais je ne l'avais pas encore promis au patient ☐ j'allais probablement y consentir ☐ j'hésitais encore si j'allais y consentir ou pas ☐ je n'allais probablement pas y consentir ☐ j'avais décidé de ne pas agréer mais je ne l'avais pas encore dit au patient ☐ j'avais déjà dit au patient que je n'allais pas consentir à sa demande ☐ je ne sais pas
25	Avez-vous consulté un confrère (2ième médecin)?	☐ oui ☐ non → ***passez à la question 32***
26	Connaissiez-vous ce médecin *(plusieurs réponses possibles)*	☐ non ☐ oui, collègue de mon hôpital ☐ oui, uniquement de nom ☐ oui, j'avais déjà fais appel à lui précédement ☐ oui, collègue de la règion ☐ oui, un collègue et ami ☐ oui, collègue de ma pratique ☐ oui, autrement
27	Le médecin connaissait-il le patient?	☐ non ☐ oui, en tant que collègue soignant ☐ oui, autrement:
28	Quelle était la spécialité de ce médecin?	☐ généraliste ☐ autre spécialité:
29	Le 2ième médecin a-t-il effectué les activités suivantes?	

	oui	non	ne sais pas
concertation avec vous	☐	☐	☐
prise de connaissance du dossier du patient	☐	☐	☐
entretien avec le patient	☐	☐	☐
examen physique du patient	☐	☐	☐
entretien avec la famille/les proches du patient	☐	☐	☐
entretien avec l'équipe de soins	☐	☐	☐
entretien avec un autre médecin traitant (spécialiste, généraliste)	☐	☐	☐
demande d'un avis auprès d'un 3ième médecin	☐	☐	☐
présence au moment de l'euthanasie	☐	☐	☐
aide pratique dans l'acte d'euthanasie	☐	☐	☐
rédaction d'un compte rendu écrit de la consultation	☐	☐	☐
aide à remplir le formulaire de régistration de déclaration pour la Commission fédérale	☐	☐	☐
autre :			

30	Quel était l'avis du 2ième médecin? *(plusieurs réponses possibles)*	☐ il trouvait que toutes les conditions de la loi relative à l'euthanasie avaient été remplies ☐ il trouvait que toutes les conditions de la loi relative à l'euthanasie n'avaient pas (encore) été remplies, à savoir : ○ pas de souffrance insupportable ○ pas de situation médicale sans issue ○ pas de demande volontaire ○ pas de demande réfléchie ○ patient était dans l'incapacité d'exprimer sa volonté ○ il y avait encore des possibilités de soins palliatifs ○ autre: ☐ n'a pas donné d'avis

31	Dans quelle mesure l'avis du 2ième médecin a-t-il influencé sur votre décision finale?	☐ dans une large mesure ☐ quelque peu ☐ à peine ☐ pas
32	Avez-vous gardé un compte rendu de votre processus décisionnel?	☐ oui ☐ non
33	l'Euthanasie a-t-elle finalement été pratiquée ?	☐ oui, par moi-même ☐ oui, mais par un autre médecin ☐ non, j'ai refusé la demande → ***passez à la question 35*** ☐ non, le patient ne désirait plus une euthanasie → ***passez à la question 35*** ☐ non, le patient est décédé avant que l'euthanasie ne soit appliquée → ***passez à la question 36*** ☐ non, le patient vit encore → ***passez à la question 36***
34	Avez-vous déclaré ce décès à la Commission Fédérale de Contrôle et d'Evaluation d'Euthanasie ?	☐ oui → ***passez à la question 38*** ☐ non → ***passez à la question 36***
35	Avez-vous pris une autre décision médicale ayant pour effet éventuel d'abréger la vie? *(plusieurs réponses possibles)*	☐ oui, une décision de non-traitement (y compris arrêt d 'une alimentation et/ou hydratation artificielle) ☐ oui, une intensification du traitement de la douleur et/ou des symptômes, en sachant que cette décision pouvait accélérer la fin de la vie ☐ oui, une sédation profonde continue jusqu'au décès avec possible effet de vie abrégée (oui ou sans alimentation et/ou hydratation artificielle) ☐ oui, autre: ☐ non, pas d'autre décision médicale avec possible effet de vie abrégée

F. Déclaration d'euthanasie

36	Avez-vous jamais déclaré un cas d'euthanasie à la Commission Fédérale de Contrôle et d'Evaluation?	☐ non, je n'ai **jamais** déclaré un euthanasie → ***passez à la question 45*** ☐ non, j'ai **déjà pratiqué** une euthanasie, mais je ne l'ai jamais déclaré → ***passez à la question 42*** ☐ oui
37	En quelle année a eu lieu le dernier cas d'euthanasie que vous avez déclaré?	
38	En déclarent à la Commission, avez-vous fait usage du formulaire standard d'enregistrement?	☐ oui, et je l'ai obtenu ☐ par Internet ☐ par un collègue ☐ par la commission médico-éthique de mon institution ☐ autrement, à savoir: ☐ non
39	Comment avez-vous vécu la déclaration dans son ensemble (jusqu'à présent)? *(plusieurs réponses possibles)*	☐ comme une charge ☐ comme un soutien ☐ ça prend du temps ☐ comme un soulagement ☐ culpabilisante ☐ neutre ☐ atteinte à la vie privée ☐ autrement, à savoir
40	Si vous pouviez changer quelque chose à la procédure de déclaration, que changeriez-vous précisément?	
41	Vous est-il arrivé de ne pas déclarer un cas d'euthanasie depuis l'entrée en vigueur de la loi sur l'euthanasie ?	☐ non, j'ai déjà pratiqué l'euthanasie, mais je l'ai toujours déclaré → ***passez à la question 44*** ☐ oui
42	En quelle année a eu lieu le dernier cas d'euthanasie que vous n'avez pas déclaré à la Commission Fédérale de Contrôle et d'Evaluation?	

43	Quelle(s) étai(en)t la/les raison(s) pour ne pas déclarer ce cas? *(plusieurs réponses possibles)*	☐ cela implique trop de tracasseries administratives ☐ l'euthanasie est l'affaire du médecin et du patient ☐ la possibilité que toutes les conditions aient pas été remplies ☐ en raison des éventuelles conséquences juridiques ☐ autre raison, à savoir :
44	Est-il concevable que vous ne déclarez pas un cas d'euthanasie dans le futur?	☐ non ☐ oui, dans le cas où:

G. Informations de base

45	De quel sexe êtes-vous?	☐ féminin ☐ masculin
46	Quel âge avez-vous?	ans
47	Quelle est votre conviction religieuse ou philosophique?	☐ catholique ☐ protestant ☐ libre-penseur ☐ autre croyance ou philosophie ☐ croyant, mais pas de religion spécifique ☐ pas de croyance
48	A l'exeption de circonstances telles qu'un mariage, un enterrement ou un baptême, à quelle fréquence assistez-vous à un service religieux ?	☐ plus d'une fois par semaine ☐ une fois par an ☐ une fois par semaine ☐ moins d'une fois par an ☐ une fois par mois ☐ jamais, pratiquement jamais ☐ uniquement à Noël/Pâques ou pour une autre occasion religieuse spéciale

H. Pour terminer

Si vos réponses aux questions nécessitent, selon vous, de plus amples explications, veuillez les donner ci-après :

FIN

Merci de votre coopération. Vous pouvez nous renvoyer le questionnaire dans l'enveloppe jointe (inutile d'affranchir)

Curriculum vitae

Yanna Van Wesemael, born January 13th 1981, studied Latin-Mathematics at the KTA Geraardsbergen. She obtained a Master's degree in Clinical Psychology at the Vrije Universiteit Brussel (2004) and a bachelor degree in Social Profit Management at the Hogeschool Gent (2005). She worked half-time as a care worker at the Centrum voor Algemeen Welzijnswerk Mozaiëk in Brussels. In September 2005, she started her academic career at the Research Centre for Gender and Diversity at the VUB, working on a European project on equal opportunities in universities. In September 2007, she became a Phd-student at the End-of-Life Care Research Group, Ghent University & Vrije Universiteit Brussel, working on a project evaluating the consultation process between physicians in euthanasia requests within the Monitoring End of Life Care project.

List of publications

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