SUPPORT AND CONTROL IN ASSISTED DYING AND PALLIATIVE SEDATION: CURRENT PRACTICES AND POTENTIAL FOR IMPROVEMENT

Stijn Vissers

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SUPPORT AND CONTROL IN ASSISTED DYING AND PALLIATIVE SEDATION

Current practices and potential for improvement

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Supervisors

Prof. Luc Deliens
Vrije Universiteit Brussel, Faculty of Medicine and Pharmacy,
End-of-Life Care Research Group

Prof. Kenneth Chambaere
Universiteit Gent, Faculty of Medicine and Health Sciences,
End-of-Life Care Research Group

Co-supervisors

Prof. Joachim Cohen
Vrije Universiteit Brussel, Faculty of Medicine and Pharmacy,
End-of-Life Care Research Group

Dr. Sigrid Dierickx
Universiteit Gent, Faculty of Medicine and Health Sciences,
End-of-Life Care Research Group

Examination committee

Chair **Prof. Dirk Devroey**
Vrije Universiteit Brussel

Members **Prof. Koen Pardon**
Vrije Universiteit Brussel

Prof. Kasper Raus
Universiteit Gent

Prof. Anja Velghe
Universiteit Gent

Dr. Roeline Pasman
Vrije Universiteit Amsterdam

Prof. Bernadette Dierckx de Casterlé
Katholieke Universiteit Leuven

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CONTENTS

LIST OF ABBREVIATIONS

CVA	Cerebrovascular accident
CDS	Continuous deep sedation until death
CI	Confidence Interval
EAPC	European Association for Palliative Care
FCECE	Federal Control and Evaluation Commission on Euthanasia
GP	General practitioner
HCP	Healthcare professional
ICU	Intensive Care Unit
LEIF	LevensEinde InformatieForum or Life End Information Forum
NIHDI	National Institute for Health and Disability Insurance
OR	Odds ratio
UK	United Kingdom
US	United States
SCEN	Support and Consultation on Euthanasia in the Netherlands

Chapters 2 – 7 are based on the following publications

Chapter 2

Vissers, S., Dierickx, S., Deliens, L., Mortier, F., Cohen, J., & Chambaere, K. (2023). Characteristics and outcomes of peer consultations for assisted dying request assessments: Cross-sectional survey study among attending physicians. *Frontiers in Public Health*, 11. (Epub ahead of print) https://doi.org/10.3389/fpubh.2023.1100353

Chapter 3

Vissers, S., Dierickx, S., Chambaere, K., Deliens, L., Mortier, F., & Cohen, J. (2022). Assisted dying request assessments by trained consultants: changes in practice and quality-Repeated cross-sectional surveys (2008–2019). *BMJ Supportive & Palliative Care*. (Epub ahead of print) http://dx.doi.org/10.1136/spcare-2021-003502

Chapter 4

Vissers, S., Gilissen, J., Cohen, J., Deliens, L., Mortier, F., Chambaere, K., Dierickx, S (2023). Support needs experienced by patients requesting euthanasia and relatives throughout the euthanasia trajectory: a qualitative study using semi-structured interviews and written narratives. (Submitted)

Chapter 5

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Chapter 6

Vissers, S., Robijn, L., Dierickx, S., Mortier, F., Cohen, J., Deliens, L., & Chambaere, K. (2021). Control Measures for Continuous Deep Sedation Until Death: A Framing Analysis of the Views of Physicians. *Qualitative Health Research*, 31(13), 2390-2402. https://doi.org/10.1177/10497323211037648

Chapter 7

Vissers, S., Dierickx, S., Robijn, L., Cohen, J., Deliens, L., Mortier, F., & Chambaere, K. (2022). Physicians' Experiences and Perceptions of Environmental Factors Affecting Their Practices of Continuous Deep Sedation until Death: A Secondary Qualitative Analysis of an Interview Study. *International Journal of Environmental Research and Public Health*, 19(9), 5472. https://doi.org/10.3390/ijerph19095472

PART I

GENERAL INTRODUCTION

Chapter 1

Background and methods

Introduction

In recent decades, assisted dying -including euthanasia and physician-assisted suicide- and continuous deep sedation until death (CDS) -a specific type of palliative sedation- have become increasingly important medical practices at the end of life. However, empirical research has shown that patients, relatives, and healthcare professionals (HCPs) involved may encounter various difficulties and challenges in these practices. These difficulties and challenges are believed to be partly linked to the control and support practices within these medical practices. In general, control practices –also referred to as control mechanisms or measures- are practices that control, manage, or regulate specific goals or objectives to ensure that individuals or processes align with predefined criteria. Their primary purpose is to monitor performance, to detect deviations from predefined criteria, and to take corrective actions when required.[1] On the other hand, support practices are practices providing assistance, help, and guidance to individuals or processes to ensure and improve their quality of life (for individuals) or their qualitative performances (for processes). Hence, in the context of euthanasia and CDS, there is a growing consensus that both could greatly benefit from a better comprehension of their control and support practices in order to address their potential for improvement. These issues have prompted the two main aims of this dissertation:

1. To describe current practices of control and support in euthanasia and to explore their potential for improvement in Flanders and Brussels, Belgium.
2. To describe current practices of control and support in CDS and to explore their potential for improvement in Belgium.

Hence, the focal points of this dissertation are the control and support practices of euthanasia and CDS. With regard to control and support practices in euthanasia, we will specifically focus on the peer consultations to assess euthanasia requests from the experiences of attending physicians and trained consultants, the support needs of patients requesting euthanasia and their relatives, and the good practices in euthanasia deployed by HCPs. With regard to control practices and support practices in CDS, we will specifically focus on possible control measures for CDS and the environmental factors affecting physician's CDS practices. Before elaborating upon euthanasia and CDS practices in-depth in the following sections, we will first outline the broader societal and historical context in which these practices are situated and how these practices are related to other medical end-of-life practices and decisions.

Background

1. Changes in ways of dying

Since the mid-1950s, there has been a radical change in the ways of dying in Western societies. Demographic, epidemiological, and socio-cultural transitions have nurtured this radical change.[1,2]

The demographic transition has been marked by a substantial increase in life expectancy at birth,[3] meaning that mortality has decreased over time.[4] The demographic transition can be attributed to improvements in public health, medical care, education, sanitation, nutrition, and access to water.[5] Populations in most Western societies now have mean life expectancies of over 80 years.[4] In Belgium, for example, the life expectancy at birth has risen from 70 years in 1960 to 81 years in 2015.[1] Due to this demographic transition, populations are thus rapidly growing and aging.[5] As a result, people are now living longer, and their end-of-life trajectories are more characterized by age-related conditions than in the past.[2]

The epidemiological transition refers to a change in causes of death.[2] Nowadays, people in Western societies more often die from non-communicable conditions –e.g., cardiovascular diseases, chronic diseases, and cancer- than from communicable conditions –e.g., infectious diseases-.[6] Due to this epidemiological transition, dying trajectories are now rather slow and degenerative processes.[6] It has been estimated that about seven out of ten deaths are non-sudden.[7] Furthermore, people experience more prolonged morbidity and disease burdens.[7] They have extended life trajectories with less good health and more disabilities, resulting in increased suffering prior to death.[8]

Several socio-cultural transitions have also occurred.[1,2] The first sociocultural transition concerns an increasing medicalization.[9] This refers to the greater involvement of medicine and medical professions in life domains that were previously considered beyond its scope.[10,11] Medicalization is embedded in the emergence of modern medicine as part of societal modernization.[9,10] This process has been marked by secularization, the growing belief in medicine as a scientific field, the growing prestige and influence of medical professions, and the increased utilization and implementation of medical technology.[9,10] Medicalization has also extended to the end of life.[12,13] Nowadays, persons more often die in medicalized and institutionalized settings –e.g., hospitals and nursing facilities- than in non-medicalized settings –e.g., home settings-.[14,15] In other words, more persons experience a medicalized death.[7] Due to this medicalization, death and dying are mainly approached in Western societies as medical-technical issues rather than existential and personal experiences.[2] This has led to the societal view that death is a failure and should be resisted, postponed, and avoided.[15] This has created a societal taboo and stigma surrounding death and dying.[16,17] As a reaction to the medicalization of the end of life, there has been a gradual shift from a medical-rationalist discourse towards a medical-revivalist one.[18] This implies that a good death is more often defined in terms of control, autonomy, dignity, awareness, and heroism, than as the natural outcome of a disease that should be medically treated.[18,19] The medical-revivalist discourse is reflected, for example, in the ethos of palliative care and right-to-die movements emphasizing the acceptance of death as a meaningful aspect of life.[12,16] The second sociocultural transition is the increasing focus on well-being.[20–22] In the context of medicine and the end of life, the emphasis is less on illness, disability, disease, and quantity of life, but instead on improving well-being and quality of life.[22] Finally, the third sociocultural transition concerns increasing individualism.[23] There has been a stronger focus on personal autonomy, the idea of the self, independence, self-determination, individual freedom, person-centeredness, and self-governance.[23] With regard to the end of life, the common belief is that individuals should be in charge of their end-of-life trajectories, decision-making at the end of life, and the dying process.[24] This is echoed, for example, in the increasing enactment of palliative care laws, assisted dying laws, and laws safeguarding the right to refuse life-saving and life-sustaining treatments.[25]

2. Typology of medical end-of-life decisions and practices

As pointed out above, the end of life can be characterized by a prolonged period of illness, disabilities, disease burdens, suffering, and intense involvement of medical professions.[2,21] Consequently, patients, relatives, or HCPs may experience that minimal quality of life is unattainable and prolonging life no longer appears sensible. In that context, they can choose to proceed with a specific medical end-of-life practice or decision with a potential or inevitable life-shortening outcome.[26]

Following the typology of van der Maas et al.- which is broadly recognized among academic scholars-,[26] medical end-of-life practices and decisions can be classified into the following main categories:

1. Withholding or withdrawing medical treatment (non-treatment decision).[26] These are medical decisions to forgo or discontinue treatments that may save or prolong life.[20] Examples of such decisions are forgoing radiation or chemotherapy, stopping artificial respiration, declining resuscitation, not starting up antibiotics, forgoing artificial hydration and nutrition, stopping mechanical ventilation, and declining CPR.[7,20] Moreover, these decisions can be made with the

possibility that the patient might die or with the explicit intention of allowing the patient to die naturally.[20]

2. Intensified pain and/or symptom management.[26] These are medical decisions to alleviate and/or treat severe pain or other symptoms through the administration of drugs.[20] This may result in a life-shortening outcome.[7,20] This is also known as the doctrine of double effect: high doses of pain-relieving drugs can be administered, even if this could lead to death, as long as the primary intention is to relieve the patient's suffering.[27] A particular form of this medical end-of-life decision is palliative sedation.[20] Palliative sedation involves the intentional administration of sedative drugs to reduce a person's consciousness at the end of life to relieve their unbearable suffering from refractory symptoms.[28]
3. Voluntary stopping eating and drinking (self-starvation).[26] These are medical decisions in which the patient chooses to stop the intake of food and fluids voluntarily and to intentionally hasten their own death.[20]
4. Assisted dying.[26] These are medical decisions in which lethal drugs are intentionally used to hasten the patient's death at the explicit and voluntary request of the patient.[20] Other terms include 'physician-assisted death', 'medical aid in dying', 'medically assisted dying', 'medically assisted death', and 'medical assistance in dying'.[20] This practice can be further divided into:
    Euthanasia: another person than the patient, most often a physician, administers the lethal drugs to end the patient's life at the voluntary and explicit request of the patient.[20]
    Physician-assisted suicide: the physician provides or prescribes lethal drugs to a patient at their voluntary and explicit request, who subsequently self-administers these drugs to end their own life.[20]
5. Active hastening of death without explicit patient request.[20,26] Lethal drugs are used without the patient's explicit request –and thus consent- to intentionally hasten the patient's death.[7,20]

Although this typology clearly distinguishes different types of medical end-of-life decisions and practices, empirical studies have shown that, in practice, there can be an overlap or grey zone among them.[7]

Thus, medical end-of-life decisions and practices play an important role at the end of life. In Belgium, for example, a study from Chambaere et al. in 2013 has estimated that about one out of two deaths annually are preceded by a medical end-of-life decision or practice: 17% of all deaths by withholding or withdrawing medical treatment, 24% by intensified pain and/or symptom management (12% by palliative sedation), 5% by assisted dying, 2% by active hastening of death without explicit patient request, 1% by voluntary stopping eating and drinking.[7,29]

3. Assisted dying

As this dissertation covers the topic of assisted dying – with a particular emphasis on euthanasia-, we will commence by providing a brief description of the status of assisted dying around the world. Subsequently, we will provide a brief overview of the status of assisted dying in Belgium, where we collected the data in this dissertation. Next, we will elaborate upon the peer consultation practice as a means of control in euthanasia practice. More specifically, we will discuss the peer consultation practice involving Life End Information Forum (LEIF) physicians, as this will be a key focus of this dissertation. The rationale of this dissertation will be discussed interwoven with the background.

3.1. Assisted dying around the world

Over recent decades, assisted dying – including euthanasia and physician-assisted suicide- has become an increasingly lawful practice worldwide.[7] Switzerland was the first jurisdiction to allow assisted dying in 1942 (decriminalization), while Portugal is the most recent jurisdiction to allow it in 2023.[30–32] In other words, it has been more than 80 years since the first framework for assisted dying was established. An overview of the jurisdictions with a legal framework for assisted dying can be found in Table 1.[30,31] These jurisdictions are home to approximately 300 million people, accounting for about 4% of the world population.[7] The jurisdictions are mainly located in Europe, America, and Australia. This number of jurisdictions allowing assisted dying is expected to increase in the coming years as other jurisdictions are currently holding public and political debates regarding the implementation of a legal framework for assisted dying, such as in the United Kingdom and several states in the United States (US) –e.g., New York State, Massachusetts, North Carolina, and Nevada-.[33,34]

Table 1. Jurisdictions with a legal framework for assisted dying

Jurisdiction	Year of enactment	Euthanasia and/or PAS*	Type of legal framework
Europe			
Switzerland	1942	PAS	Decriminalization
Netherlands	2002	Euthanasia & PAS	Legislation
Belgium	2002	Euthanasia & PAS	Legislation
Luxembourg	2009	Euthanasia & PAS	Legislation
Germany	2020	PAS	Decriminalization
Italy	2019	PAS	Decriminalization
Spain	2021	Euthanasia & PAS	Legislation
Austria	2021	PAS	Legislation
Portugal	2023	Euthanasia & PAS	Legislation
America			
Canada	2016	Euthanasia & PAS	Legislation
Colombia	1997	Euthanasia & PAS	Court ruling
United States			
Oregon	1997	PAS	Legislation
Washington	2009	PAS	Legislation
Montana	2009	PAS	Court ruling
Vermont	2013	PAS	Legislation

California	2015	PAS	Legislation
Colorado	2016	PAS	Legislation
District of Colombia	2016	PAS	Legislation
Hawaii	2018	PAS	Legislation
Maine	2018	PAS	Legislation
New Jersey	2019	PAS	Legislation
New Mexico	2021	PAS	Legislation
Australia**			
Queensland	2021	Euthanasia & PAS	Legislation
Tasmania	2021	Euthanasia & PAS	Legislation
Victoria	2017	Euthanasia & PAS	Legislation
Western Australia	2019	Euthanasia & PAS	Legislation
South Australia	2021	Euthanasia & PAS	Legislation
New Zealand	2019	Euthanasia & PAS	Legislation

Source: own table based on Mroz et al.[30,31]

*PAS: physician-assisted suicide

**In 2022, the Parliaments of the Northern Territory and Australian Capital Territory overturned a ban on the right to enact their own assisted dying legislation. Both states are currently debating the details and implementation of such legislation.[35]

While scientific literature commonly employs the umbrella term 'assisted dying', legal frameworks utilize their own distinct terminology to refer to this practice, for instance, ‘euthanasia’ in Belgium, ‘death with dignity’ in Oregon, ‘medical assistance in dying’ (MAID) in Canada, ‘assisted suicide’ in Switzerland, ‘physician aid in dying’ in Montana, and ‘voluntary assisted dying’ in Victoria (Australia).[32] This reflects the trend towards adopting more neutral terms, such as ‘medical aid in dying’, instead of using the term ‘suicide,[36] due to their reduced stigma and greater inclusivity.[32]

When it comes to the eligibility for assisted dying –i.e., substantive requirements-, all these jurisdictions grant access to persons with a terminal illness caused by somatic disorders.[31] In the US, Colombia, and Victoria (Australia), the person must be believed to be in a state of imminent death.[31] In Belgium, the Netherlands, Luxembourg, and Canada, patients with a psychiatric condition and dementia can also have access to assisted dying if they have the mental capacity.[30,31] Only in the Netherlands, patients with a loss of mental capacity due to severe dementia can also receive assisted dying based on the basis of an advance assisted dying directive.[37] Furthermore, other similarities among substantive requirements in jurisdictions are: the assisted dying request must be voluntary, well-considered, and repeated over time; the person must experience intolerable physical or psychological suffering that cannot be alleviated (though not required for access to assisted dying in the US), the physician is required to communicate the person's medical condition and available treatment options, and both parties must have mutually acknowledged that there is no reasonable expectation of improvement.[31] In addition, similarities among procedural requirements in jurisdictions are: the performing physician must consult a second independent physician prior to the act of assisted dying, and must report the assisted dying case for review to a multidisciplinary evaluation commission.[31]

Empirical studies and publications of evaluation commissions have indicated that the prevalence of assisted dying is rising in nearly all jurisdictions where the practice is lawful.[7,31] The prevalence of assisted dying varies across jurisdictions, ranging from 0.1% of all deaths (in one year) in California (US) to 4.0% of all deaths in the Netherlands.[31] These figures are likely higher in reality due to potential underreporting.[38] Furthermore, studies have demonstrated an increasing acceptance of assisted dying among the general public in these jurisdictions over the years, which may partially explain the increase in the number of individuals requesting it.[39]

3.2. The legal context of euthanasia in Belgium

Belgium is one of the jurisdictions across the globe where euthanasia is legal. This practice has been legally regulated by the Belgian Act on Euthanasia, enacted on May 28, 2002.[30] Most likely, two factors played a crucial role in this process of legalization: 1) the widespread support of the public for such change, and 2) the political circumstances allowing for change to take place.[40] The latter will be discussed in the following sections.

The process towards the Belgian Act on Euthanasia commenced in the 1980s with the emergence of two right-to-die movements advocating for euthanasia: ‘Recht op Waardig Sterven’ in Flanders and ‘Association pour le Droit de Mourir’ in Wallonia.[41,42] Although several euthanasia bills were submitted by Liberal and Social-Democrat members in the Federal Parliament over the next twenty years, none was successfully passed due to strong opposition from the Christian Democrats, the most prominent political fraction in the government.[41,42] In 1997, the Federal Advisory Commission on Bioethics assessed the desirability of accepting euthanasia legislation but could not reach a consensus among its members.[41,42] Therefore, the Commission put forward four proposals for the legal regulation of euthanasia practice (Table 2).[41,42] These proposals facilitated discussions in the Belgian Senate. Following the federal elections in 1999, a coalition of Greens, Liberals, and Social Democrats was established without Christian Democrats.[41,42] This coalition drafted seven different bills based on the four proposals of the Federal Advisory Commission on Bioethics.[41] The Belgian Senate finally accepted a euthanasia bill in October 2001, and the Belgian House of Representatives, the lower house of Parliament, on May 28, 2002.[41,42] The acceptance of this bill was partly expedited by a study on medical end-of-life decisions in Flanders in 1998, which had revealed that physicians were already carrying out euthanasia without legal regulation.[43] The study estimated that 1.3% of all deaths annually were preceded by euthanasia or physician-assisted suicide.[43] Lawmakers considered it undesirable that there was a clandestine practice in which physicians were performing euthanasia on their own terms, and aimed to establish more transparency and societal control regarding euthanasia performances.[41,42] As a result, the Belgian Act on Euthanasia took effect on September 23, 2002. As such, Belgium was the second jurisdiction in the world to allow euthanasia, following the Netherlands, where assisted dying legislation had been approved a few months before. Shortly after this, the Belgian Laws on Palliative Care and Patient Rights was also accepted on June 14, 2002.[44,45] The Belgian Law on Palliative Care ensures that patients at the end of life have the right to receive palliative care.[45] Moreover, it states that palliative care should be widely available and reimbursed by social security services to ensure equal access for all patients with a terminal condition.[45] On the other hand, the Belgian Law on Patient Rights grants several rights to patients.[44] These rights include, for example, receiving quality services that meet their needs and respect their dignity and self-determination without any form of discrimination, having the freedom to choose and change HCPs, obtaining all necessary health information from their HCPs, and having access to securely maintained patient records from their HCPs.[44]

Table 2. Four proposals for the legal regulation of euthanasia practice in Belgium, as formulated by the Federal Advisory Commission on Bioethics in 1997

1. Provide legal certainty that makes euthanasia no longer punishable by amending the Belgian Penal Code, and determine the legal requirements under which euthanasia is lawful.
2. Retain the existing restrictions that prohibit euthanasia in the Belgian Penal Code, but implement specific legal requirements allowing physicians to perform euthanasia in the context of an emergency. Furthermore, a posteriori control procedure should be implemented in which the physician has to report the euthanasia case to the judicial authorities following the performance.
3. Uphold the existing restrictions that consider all medical end-of-life decisions, including euthanasia, as a criminal offense in the Belgian Penal Code, but set out the legal requirements for physicians to invoke the state of emergence for a specific medical end-of-life decision. Moreover, a priori evaluation by a third person appointed by the local ethical commission should be implemented to assess the euthanasia request, as well as a posteriori societal or judicial evaluation.
4. Decline any form of euthanasia because of the sanctity of human life, but seek alternative means to alleviate a patient's suffering, such as palliative care.

Source: own table based on Saad[41]

In the current Belgian Act on Euthanasia, euthanasia is defined as intentionally terminating life by someone other than the person concerned at the latter's request.[46] Moreover, the act stipulates that only physicians can perform euthanasia and that they do not commit a criminal offense if specific legal requirements are met (Table 3).[46] In this regard, it should be noted that there is no right to euthanasia in Belgium. This implies that a patient cannot legally compel a physician to perform euthanasia. Thus, a physician has the right to refuse participation in euthanasia practice.[47] This also applies to other HCPs, as no one can be compelled to assist in euthanasia practice. However, if physicians refuse to assess a euthanasia request on the grounds of freedom of conscience, they have to inform the patient about the motives of this refusal within seven days of the initial request.[47] If physicians refuse to perform euthanasia based on medical grounds following assessment, they have to inform the patient about the motives of their refusal promptly.[47] In addition, physicians declining the euthanasia request have to provide the patient with the contact details of a center specializing in euthanasia legislation, and the medical records of the patient to their new attending physician upon the request of the patient.[47]

Table 3. Legal requirements stipulated in the Belgian Act on Euthanasia

The physician who performs euthanasia commits no criminal offence when s/he ensures that:

the patient has attained the age of majority or is an emancipated minor, who is legally competent and is conscious at the time of making the request;

the request is voluntary, well-considered and repeated, and is not the result of any external coercion;

the patient is in a medically futile condition of persistent and unbearable physical or psychological suffering that cannot be alleviated, resulting from a severe and incurable condition caused by illness or accident;

s/he has respected the conditions and procedures as provided in this Act on Euthanasia.

Without prejudice to any additional conditions imposed by the physician on his/her own action, before carrying out euthanasia he/she must in each case:

inform the patient about their health condition and life expectancy, and discuss with the patient his/her request for euthanasia and the possible therapeutic and palliative courses of action and their consequences. Together with the patient, the physician must come to the belief that there is no reasonable alternative to the patient's situation and that the patient's request is entirely voluntary;

be certain of the patient's persistent and unbearable physical or psychological suffering and of the durable nature of his/her request. To this end, the physician has several conversations with the patient spread out over a reasonable period of time, taking into account the progress of the patient's condition;

consult another physician about the severe and incurable nature of the condition and inform him/her about the reasons for this consultation. The physician consulted reviews the medical record, examines the patient, and must be certain of the patient's persistent and unbearable physical or psychological suffering that cannot be alleviated. The physician consulted reports on their findings. The physician consulted must be independent of the patient as well as of the attending physician and must be competent to give an opinion about the disorder in question. The attending physician informs the patient about the results of this consultation;

if there is a nursing team that has regular contact with the patient; discuss the request of the patient with the nursing team or its members;

if the patient so desires, discuss their request with relatives appointed by the patient;

be certain that the patient has had the opportunity to discuss his/her request with the persons that s/he wanted to meet.

If the physician believes the patient is clearly not expected to die in the near future, he/she must also:

consult a second physician, a psychiatrist or a specialist in the disorder in question, and inform him/her of the reasons for such a consultation. The consulted physician reviews the medical record, examines the patient, and must ensure himself about the persistent and unbearable physical or psychological suffering that cannot be alleviated, and of the voluntary, well-considered, and repeated nature of the euthanasia request. The consulted physician reports on his/her findings. The consulted physician must be independent of the patient as well as of the physician initially consulted. The physician informs the patient about the results of this consultation;

allow at least one month between the patient's written request and the act of euthanasia.

The patient's request must be in writing:

The document is drawn up, dated, and signed by the patient himself/herself.

If the patient is not capable of doing this, the document is drawn up by a person designated by the patient. This person must have attained the age of majority and must not have any material interest in the death of the patient. This person indicates that the patient is incapable of formulating his/her request in writing and the reasons why. In such a case, the request is drafted in the presence of the physician whose name is mentioned on the document. This document must be annexed to the medical record.

The patient may revoke his/her request at any time, in which case the document is removed from the medical record and returned to the patient.

After performing euthanasia, the attending physician must notify the case for review to the Belgian Federal Control and Evaluation Commission for Euthanasia.

<u>Source:</u> own table based on the Belgian Act on Euthanasia[46]

The Belgian Act on Euthanasia outlines the specific substantive requirements for euthanasia, which are the conditions that must be met in each euthanasia case.[46] First, the patient must be an adult or an emancipated minor who is legally competent and conscious when expressing the initial euthanasia request.[41,46] Secondly, the euthanasia request has to be well-considered, repeated, and not the result of external coercion.[41,46] Thirdly, the patient needs to be in a medically futile condition of persistent and unbearable physical or psychological suffering that cannot be alleviated, resulting from a severe and incurable condition caused by illness or accident.[41,46] In 2014, the Belgian Act on Euthanasia was extended to non-emancipated minors (sometimes referred to as 'competent' or 'capable' minors), regardless of age, to have access to euthanasia.[48] More specifically, non-emancipated minors may have access to euthanasia if 1) they have the capacity for discernment; 2) they are in a hopeless medical situation of persistent and unbearable physical suffering that cannot be alleviated; and that will shortly lead to death, and that stems from a severe and incurable condition caused by illness or accident; 3) the capacity for discernment has been confirmed by a child and adolescent psychiatrist or psychologist; 4) the legal representatives –e.g., parents or guardians- provide consent to performing euthanasia; and 5) the legal representatives have been offered the opportunity to receive psychological support following the euthanasia request.[46,48]

In addition to the substantive requirements, the Belgian Act on Euthanasia also states procedural requirements. The procedural requirement for the patient is to document their euthanasia request for euthanasia in writing.[46] The procedural requirements that the attending physician must follow prior to the performance of euthanasia are: 1) informing the patient of their condition, discussing therapeutic and palliative options with the patient, determining that there are no alternatives to the patient's situation, and ensuring that there is no external pressure; 2) establishing certainty about the patient's condition through several conversations with the patient; 3) holding a peer consultation with another physician (for more details about this peer consultation, see section 3.4); 4) discussing the euthanasia request with members of the nursing team if they have had regular contact with the patient; 5) discussing the euthanasia request with the patient's relatives if the patient wishes this; 6) ensuring that the patient has the opportunity to discuss the euthanasia request with the individuals of their choice.[41,46] Following the performance of euthanasia, the physician has to report the euthanasia case to the Federal Control and Evaluation Commission on Euthanasia (FCECE) as a procedural requirement.[46] As concerns this reporting procedure, the physician must complete a registration form and send it to the FCECE within four days after the performance of euthanasia.[46] This registration form comprises two parts. The first part is a confidential section that includes the personal details of the patient, the physicians involved, the pharmacist who provided the lethal medication, other HCPs, informal caregivers, and relatives.[46] The second part is an anonymous section that includes all the important details of the case on which the attending physician relied to carry out euthanasia.[46] Based on the details in the second part (the anonymous section), the FCECE verifies whether the euthanasia case meets all legal requirements.[46] In case of doubt, the FCECE may vote by a majority to review the first part (the confidential section). Following the review of the first part, the FCECE may request additional information from the attending physician or require the attending physician to be questioned in person.[46] If two thirds of members of the FCECE believe that euthanasia was not carried out in accordance with the Belgian Act on Euthanasia, the FCECE may inform the public Prosecutor about the euthanasia case.[46]

The Belgian Act on Euthanasia includes an additional procedural requirement if the physician determines that the patient requesting euthanasia will not die in the near future –i.e., patients with a non-terminal illness-. In addition to the first peer consultation, the attending physician must hold a second peer consultation with another physician (for more details about this peer consultation, see section 3.4).[46] Furthermore, the attending physician must ensure a one-month waiting period between the euthanasia request and the actual performance of euthanasia.[46]

Next to an actual euthanasia request, the Belgian Act on Euthanasia stipulates that a physician can also perform euthanasia based on a written advance euthanasia directive.[46] This directive must be in writing and signed by two adult witnesses, of whom at least one cannot have a vested interest in the patient's death.[46] To remain valid, advance directives drafted before April 2, 2020, must be reaffirmed within five years.[46] Those that were drafted after that date will remain valid for an unlimited period of time.[46] In this case, patients can have access to euthanasia if they suffer from a severe and incurable condition caused by accident or disease, and are in an irreversible state of unconsciousness according to science's current state of affairs.[46] All other legal requirements and procedures related to an actual request also apply to a euthanasia case based on an advance euthanasia directive. In addition, the consulted physician has to confirm that the patient is in an irreversible state of unconsciousness.[46]

The legal status of physician-assisted suicide in Belgium is somewhat unclear. On the one hand, the Belgian Act on Euthanasia does not explicitly refer to legal provisions regarding physician-assisted suicide. This was also substantiated by the Belgian Federal Public Prosecutor in 2015. In that particular case, an attending physician who had engaged in physician-assisted suicide was dismissed from further legal proceedings. The Belgian Prosecutor deemed this act to be outside the scope of the euthanasia legislation. On the other hand, the FCECE, a legally mandated entity under the Belgian Act on Euthanasia, has stated that it approaches physician-assisted suicide equivalent to euthanasia and that such a case should comply with the legal requirements for euthanasia.[49] The FCECE claims that the Belgian Act on Euthanasia permits physician-assisted suicide as it does not prescribe the specific method for administering lethal drugs.[49] The FCECE also postulates that a physician must be present when the patient self-administers the lethal medication to intervene if necessary.[49] In addition, the National Council of the College of Physicians, a legally mandated entity, has expressed similar assertions, stating that physicians may practice physician-assisted suicide as long as they comply with the legal requirement for euthanasia and closely monitor the self-administration of the lethal drugs.[50]

3.3. Euthanasia practice in Belgium: evolution of prevalence and patient profiles

We can observe two distinct evolutions in assisted dying practice since its implementation in Belgium.[51,52]

The first evolution concerns that there has been a consistent increase in the number of euthanasia cases, rising from 235 in 2003 (which accounts for 0.2% of all deaths) to 2966 in 2022 (which accounts for 2.5% of all deaths).[52,53] This evolution reflects an initial phase of gradual acceptance and adoption of euthanasia practice, followed by a broader implementation phase as physicians and the overall healthcare system become more familiar and comfortable with the legal and moral boundaries.[30] Possibly, various factors have contributed to this evolution, including reduced barriers, evolving attitudes, increased acceptance among medical professionals and the population, growing familiarity among physicians, education and training, professional support systems, and reduced legal concerns when following care criteria.[30]

The second evolution concerns that the profiles of patients requesting euthanasia have changed.[51,52] In the first years following implementation, the vast majority of persons receiving euthanasia were those with cancer as the principal diagnosis.[51,52] Although this patient group still accounts for the highest numbers of patients receiving euthanasia, studies have indicated a trend towards higher numbers for other patient groups with other medical conditions, such as old age-related multimorbidity, psychiatric disorders, dementia-related conditions, and cardiovascular conditions.[30,51,52]

In 2022, the FCECE reported the following main diagnoses in patients who had received euthanasia: cancer(s) (59.9%), a combination of various chronic and incurable conditions (polypathology) (19.6%), neurological conditions (8.9%), cardiovascular conditions (3.7%), respiratory and lung diseases (3%), cognitive disorders (1.4%), psychiatric conditions (0.9%), gastrointestinal system (0.5%), musculoskeletal and connective tissue conditions (0.5%), and other conditions (1.6%).[53]

3.4. Euthanasia practice may present some challenges and difficulties for patients requesting it, their relatives, and their HCPs

Notwithstanding the increasing prevalence of assisted dying worldwide, research has shown that those involved might face difficulties, challenges, and undesired outcomes in practice. Persons requesting assisted dying (hereafter 'patients') might experience, for example, that their autonomy and values are not being respected by HCPs; that relatives minimize their unbearable suffering; that the legal requirements for assisted dying are difficult to understand; a lack of support after the attending physician has not granted the request; pressure from their relatives to withdraw their assisted dying request; loneliness during the assisted dying request assessment; fear for future suffering and disability prior to performance; a low quality of life; reluctance to discuss their assisted dying request with relatives.[54–63] Relatives of patients might experience, for example, being unprepared or ill-equipped to attend the performance of assisted dying; post-traumatic stress after the performance; not being involved by HCPs and patients during the assessment of the assisted dying request; emotional stress due to witnessing the suffering of their loved one; not being able to cope with their grief after the performance of assisted dying; that the performance of assisted dying is not in line with their expectations; strong disagreement with the final outcome of the assisted dying request assessment; feelings of surprise when they learn about the patient's desire for assisted dying; that attending physicians are reluctant to share information about the assisted dying request; feelings of regret about the course of the assessment and performance; frustration about the long duration of the assessment.[64–75] HCPs might experience, for example, emotional coping issues during the assessment and performance of assisted dying; feelings of insecurity regarding the assisted dying request assessment; difficulties with differentiating assisted dying from palliative sedation; uncertainties about their specific role in the assessment of the assisted dying request; the need for additional support to assess complex assisted dying requests; a lack of expertise to assess an assisted dying request of a patient with a non-terminal condition; difficulties with the interpretation of legal requirements for assisted dying; not having proper access to lethal medication; that their professional context prohibits them from practicing assisted dying; pressure from relatives to not proceed with the performance of assisted dying.[76–86]

As a result, scholars have pointed out that these difficulties, challenges, and undesired outcomes partly stem from ineffective and/or insufficient support provided to patients, their relatives, and their HCPs.[32,67,87,88] Therefore, their support in assisted dying practice has been suggested to hold potential for improvement. [32,67,87,88] This dissertation aims to contribute to this topic by addressing two knowledge gaps related to support in assisted dying practice. The first knowledge gap concerns that we have a limited in-depth understanding of the support needs of patients requesting assisted dying and their relatives throughout their assisted dying trajectories, i.e., from the initial expression of the patient's desire for assisted dying to the period following the performance of assisted dying. The second knowledge gap concerns that we have a limited in-depth understanding of the good practices in assisted dying, which can be defined as those practices resulting in better outcomes compared to alternative approaches. A better comprehension of the support needs and good practices, for example, can guide HCPs to anticipate and mitigate undesirable outcomes while improving the quality of life of patients and relatives. Additionally, such understanding may offer valuable insights to relatives and family caregivers on providing better support to their loved ones seeking assisted dying. Furthermore, these insights can assist jurisdictions in enhancing their care and support systems within assisted dying practice.

3.5. Peer consultation as control in euthanasia practice

The Belgian Act on Euthanasia has incorporated three control practices- also referred to as control levels, control mechanisms, or control measures- to ensure that euthanasia complies with its legal requirements.[89] The first control practice concerns 'self-control'.[89,90] This involves the attending physician controlling the patient's eligibility for euthanasia by reviewing the patient's medical records, examining the patient, and holding multiple conversations with the patient over a reasonable period of time.[89] It is a form of a priori control since it occurs before performing euthanasia.[91] The second control practice concerns peer control.[89] This involves another physician who also controls the patient's eligibility for euthanasia through a peer consultation, which is also a form of a priori control.[89] The third control practice concerns societal or judicial control.[89] This involves that FCECE controls whether the euthanasia case adheres to all the legal requirements by reviewing the registration form completed by the attending physician.[89] It is a form of a posteriori control as it is carried out following the performance of euthanasia.[91]

While peer consultation functions as a priori control in the current legal context of euthanasia practice, it is worth noting that other inherent functions or qualities of peer consultation were initially considered when incorporating it as a legal requirement.[40] First, peer consultation was considered to function as quality control.[40] Attending physicians may face difficult decisions when assessing a euthanasia request, such as diagnosing conditions and considering curative or palliative treatments.[40] Therefore, seeking advice from another physician can enhance the medical quality of the decision-making process.[40] This closely resembles the function of peer consultation in other medical practices. Second, peer consultation was deemed to be a means of fostering intersubjectivity.[40] Numerous aspects of the euthanasia request assessment involve subjective evaluations; for example, ascertaining the patient's unbearable suffering.[40] Consequently, peer consultation can ensure that the final decision to grant euthanasia is not solely dependent on the personal idiosyncrasies of the attending physician.[40] Third, peer consultation was considered to be informative.[40] For the majority of attending physicians, euthanasia is not routine practice.[40] Peer consultation can provide them with important information about euthanasia legislation they may not be aware of, for instance, the substantive requirements.[40] Fourth, peer consultation was deemed to function as a preventive and justificatory measure.[40] Being aware of the mandatory consultation, attending physicians might strive to ensure that everything has been done correctly, and they can use the advice from the consultant to explain to the patient the reasons for (not) granting euthanasia.[40] Fifth, peer consultation was considered to function as a post facto control if necessary. Peer consultation guarantees that a qualified physician is aware of the circumstances under which an attending physician has granted euthanasia.[40] This ensures that control afterward –e.g., by the FCECE- is not entirely dependent on the testimony of the attending physician.[40]

Hence, peer consultation is a control practice implemented in the Belgian Act on Euthanasia.[46] More specifically, the Act stipulates that the attending physician who agrees to proceed with the euthanasia request must hold a peer consultation with another physician (hereafter referred to as 'consultant') to assess the incurable and severe condition of the patient.[46] To that end, the attending physician is required to inform the consultant about the reasons for consulting him or her.[46] In concrete terms, the consultant must review the patient's medical records, examine the patient, and ascertain that the patient is experiencing persistent and unbearable physical or psychological suffering that cannot be alleviated.[46] The consultant must also draft a report of their findings.[46]

The Belgian Act on Euthanasia states that the consultant must be 1) independent from both the patient requesting euthanasia and the attending physician, and 2) authorized to evaluate the patient's condition. The Act does not provide a further definition of such independence. However, the FCECE deploys the following criterion to determine the independence between the attending physicians and the consultant: not having any familial or hierarchical subordinate relationship.[92] For example, the FCECE considers it not a good practice when an attending physician in training holds a peer consultation with their supervisor.[92] As for the independence between the consultant and the patient requesting euthanasia, the FCECE specifies that the patient cannot have had a previous and ongoing therapeutic relationship with the consultant.[92]

Furthermore, the Belgian Act requires the attending physicians to hold an additional or second peer consultation with another or second independent consultant for two specific patient groups: 1) patients who are not expected to die in the near future, for example, patients with psychiatric conditions; and 2) non-emancipated minors.[46] As concerns the first patient group, the second consultant has to be either a psychiatrist or a medical-specialist in the patient's condition and must review the patient's medical records, examine the patient, ascertain that the patient is experiencing persistent and unbearable physical or psychological suffering that cannot be alleviated, and ascertain that the euthanasia request has been voluntary, well-considered, and repeated.[46] The second consultant also needs to be independent from the patient, the attending physician, and the first consultant. As concerns non-emancipated minors, the second consultant should be a child and adolescent psychiatrist or psychologist, who has to review the minor's medical records, examine the minor, and ascertain that the non-emancipated minor holds capacity for discernment.[46]

Peer consultation as a form of peer control has also been implemented in the majority of frameworks for assisted dying in other jurisdictions (Table 4).[30,31] In most of these jurisdictions, the legally required peer consultation involves consulting a physician, such as in the Netherlands and Spain.[31] In contrast, in certain Canadian provinces, nurse practitioners are also allowed to serve as consultants, whereas in Colombia, attending physicians are required to hold a peer consultation with an interdisciplinary scientific committee composed of a lawyer, a physician having expertise in the patient's medical condition, and a psychiatrist or clinical psychologist.[30,31] Moreover, some jurisdictions stipulate that consultants must have a particular medical specialty or have completed special training to assess an assisted dying request.[30,31] For example, in Austria, consultants must be palliative care physicians, whereas, in some Australian states, consultants must have followed special assisted dying training developed by the public health authorities.[30,31]

Table 4. Jurisdictions where peer consultation is legally required prior to performing assisted dying

Jurisdiction	Peer consultation required
Switzerland	None specified
Netherlands	Yes
Luxembourg	Yes
Germany	None specified
Italy	None specified
Spain	Yes
Austria	Yes
Canada	Yes
Colombia	Yes
Oregon (US)	Yes
Washington (US)	Yes
Montana (US)	None specified
Vermont (US)	Yes
California (US)	Yes
Colorado (US)	Yes
District of Colombia (US)	Yes
Hawaii (US)	Yes
Maine (US)	Yes

New Jersey (US)	Yes
New Mexico (US)	Yes
Queensland (Australia)	Yes
Tasmania (Australia)	Yes
Victoria (Australia)	Yes
Western Australia (Australia)	Yes
South Australia (Australia)	Yes
New Zealand	Yes

Source: own table based on Mroz et al.[30,31]

US: United States

Despite the widespread adoption of peer consultation as a legal requirement in assisted dying practice, it is noticeable that we still have limited insights into this required peer consultation practice as it is under-researched. Moreover, the existing empirical studies are limited and have been mainly conducted in the Netherlands and Flanders (Belgium) in the initial years following the implementation of assisted dying legislation.[93,94] Furthermore, these studies have primarily relied on the accounts of consultants.[93,94] Less attention has been paid to the perspectives of attending physicians requesting these peer consultations to assess a euthanasia request. Therefore, this dissertation aims to contribute to this issue by examining the peer consultation practice. Studying the current practice of peer consultation, particularly the content of these consultations, can yield valuable insights. Firstly, it can reveal which attending physicians seek the assistance of assisted dying consultants and for what types of cases. This, for example, can identify the support needs of attending physicians when they receive an assisted dying request. Secondly, it can provide insight into how assisted dying consultants evaluate the cases for which consultation is sought, thus exploring the relationship between their advice and the specific cases. In essence, these insights can be used to identify pathways for improving care and support for patients who request assisted dying, as well as for improving support for attending physicians seeking guidance from consultants.

3.6. LEIF practice as control and support in euthanasia practice

As pointed out above, this dissertation centers for a large part on the peer consultation practice in the context of euthanasia. More specifically, the focus will be on the peer consultation practice with specially trained consultants in Flanders and Brussels –i.e., Life End Information Forum (LEIF) consultants-, also referred to as the 'LEIF practice'. We will elaborate upon LEIF in the subsequent sections.

Following the implementation of the euthanasia legislation in 2002, attending physicians receiving a euthanasia request faced uncertainty in assessing and performing it, and experienced difficulties in finding consultants to assess a euthanasia request.[95] This could be attributed to the lack of a comprehensive strategy to implement the legislation and of relevant jurisprudence to inform the interpretation of the legal requirements, as was the case in the Netherlands.[95] Therefore, palliative care advocates and the right-to-die association 'Recht op Waardig Sterven' established LEIF in 2003 in Flanders and Brussels, the Dutch-speaking part of Belgium.[96] LEIF was modeled after 'Support and Consultation in Euthanasia Network' (SCEN) in the Netherlands, which offers training to physicians in assessing an assisted dying request.[96] The initial aims of LEIF were 1) to offer special training –i.e., LEIF physician training- to ensure independent and competent consultants to assess a euthanasia request, 2) to provide consultations to physicians in various end-of-life practices, including palliative care, and 3) to provide information about end-of-life practices to the broader public.[96]

To date, LEIF continues to pursue these aims. With regard to the LEIF physician training, the program focuses on euthanasia, other end-of- life practices, and quality criteria for consultations to assess a euthanasia request.[97] It is delivered in person by experts in palliative care and euthanasia. More specifically, the training is divided into five modules (each lasting 5.5 hours), including: 1) medical end-of-life decisions, Belgian euthanasia legislation, patient rights, and access to palliative care; 2) the organization and functioning of LEIF, legal aspects of advance directives, and advance care planning; 3) ethics and the concept of mental capacity in palliative care; 4) the practical aspects of euthanasia and euthanasia research; and 5) physician communication with patients, their relatives, and other HCPs in the context of end-of-life decisions.[97] Upon completing the first two modules, physicians receive the qualification of 'LEIF consultant' or 'LEIF physician'.[97] LEIF considers this the core curriculum or the minimum standard necessary to ensure quality in peer consultations in the context of end-of-life practices. However, LEIF strongly encourages physicians to complete all modules of the training. The certified LEIF consultants can be contacted by the central management of LEIF or HCPs to 1) conduct assisted dying request assessments, and 2) offer advice and information on various end-of-life practices to patients, relatives, and HCPs.[97] As concerns the former, LEIF consultants can receive financial compensation for a euthanasia request assessment from the Belgian National Institute for Health and Disability Insurance (NIHDI). However, only those consultants that the NIHDI has licensed in advance can seek compensation.

Notably, other jurisdictions with assisted dying legislation have also adopted comparable peer consultation practices involving trained consultants to assess an assisted dying request. For example, attending physicians can consult with SCEN physicians in the Netherlands and with 'Canadian Association of MAiD Assessors and Providers' physicians and nurse practitioners in Canada.[96,98] In Victoria and Western Australia (Australia), attending physicians are required to hold a peer consultation with physicians who completed the 'Voluntary Assisted Dying Training for Medical Practitioners'.[99] The reasons for training consultants are multifold, including, for example, quality assurance in ensuring that the assessment adheres to established protocols and legal requirements; increasing the expertise of consultants; expanding the supply of consultants in practice; the professionalization and standardization of the peer consultation practice; ensuring consultants have effective communication skills to interact with attending physicians, patients, and relatives; and ascertaining they have the necessary diagnostic skills to identify problems that might have affected the assisted dying request.[93,94,98,100] In essence, the peer consultation practice with trained consultants may function either as a control practice, in which consultants ensure compliance with legal requirements, or as a support practice, in which consultants offer additional guidance tailored to the attending physician's support needs. Of course, both functions can also be fulfilled simultaneously.

4. Continuous deep sedation until death

The second focal point of this dissertation revolves around the practice of continuous deep sedation until death (CDS), which is a specific type of palliative sedation. In the following sections, we will briefly elaborate on this practice and the rationale for focusing on it in this dissertation.

4.1. Typology: CDS in relation to other types of palliative sedation

Patients near death may experience distressing symptoms, such as pain, delirium, and breathlessness.[101] Although many of these symptoms can be effectively addressed through conventional pain and symptom management, there are cases in which some of these symptoms are highly challenging to treat or do not respond to available treatment options.[102] These are known as 'refractory symptoms' because treatment does not work, takes too long to have an effect, or has unacceptable side effects for the patient.[102] Moreover, these symptoms encompass physical and non-physical suffering. Therefore, it is sometimes called intractable, unbearable, or intolerable suffering.[102] When conventional pain and symptom management are ineffective, palliative sedation can be considered.[103]

In literature, the definitions of palliative sedation exhibit variations and discrepancies.[103] However, the typology proposed by Morita et al. is widely recognized among scholars.[104] This typology attributes two fundamental elements to palliative sedation: 1) the presence of severe distress refractory to standard palliative treatment, and 2) the use of sedative medication with the primary aim of relieving that distress by reducing consciousness.[104] Furthermore, it also differentiates various types of palliative sedation based on the degree and duration of the sedation.[104] In terms of the degree or depth, it distinguishes between mild (or light) sedation and deep sedation.[104] Light sedation refers to a lower level of consciousness in which the patient can still communicate, whereas deep sedation renders a state of complete unconsciousness in which communication is no longer possible.[103] In terms of duration, the typology distinguishes between intermittent sedation and continuous sedation.[104] Intermittent sedation refers to administering sedation for a short period and allowing the patient to regain consciousness, while continuous sedation implies that sedation is maintained until the patient's death.[104] Following these criteria, we can differentiate the practice of continuous deep sedation until death.[104] This involves the practice in which sedative drugs are intentionally administered, resulting in a continuous reduction of a patient's consciousness until death in order to alleviate the unbearable suffering from refractory symptoms.[104]

Numerous guidelines, protocols, and frameworks for palliative sedation, including CDS, have been developed worldwide, outlining the specific indications and preconditions for initiating and proceeding with CDS.[28,105,106] They often differ in several aspects, such as the definitions of CDS, assessing refractory symptoms, the role of the patient in the decision-making process, the patient's required life expectancy, the need for a multidisciplinary approach, dose titration, informed consent, and the involvement of relatives and HCPs.[28,107–109] However, they generally exhibit broad similarities and alignment with the framework established by the European Association for Palliative Care (EAPC).[106,108,110] This framework was developed in 2009 and will be updated in the near future.[108,110] It consists of 10 items or recommendations for the proper use of CDS: 1) recommend pre-emptive discussion of the potential role of sedation in end-of-life care and contingency planning, 2) describe the indications in which sedation may or should be considered, 3) describe the necessary evaluation and consultation procedures, 4) specify consent requirements, 5) indicate the need to discuss the decision-making process with the patient's relative, 6) present direction for selection of the sedation method, 7) present direction for the dose titration, patient monitoring and care, 8) guidance for decisions regarding hydration and nutrition and concomitant medications; 9) the care and informational needs of the patient's family, and 10) care for the medical professionals.[110]

4.2. CDS practice in Belgium: prevalence and patient profiles

Currently, there is a lack of recent data regarding the prevalence of CDS in Belgium. However, a population-based death certificate study in Flanders estimated that CDS preceded 12% of all deaths in 2013.[29,111] The study revealed a decrease in the prevalence of CDS as 14.5% of all deaths had been preceded by CDS 2007.[29,111] In 2001, CDS was performed in 8.2% of all deaths in Flanders.[29] Belgium appears to be the only country where the prevalence has decreased over the years compared to other European countries.[112] Furthermore, this study also found that one out of four CDS cases in 2013 was performed in patients with cancer, while three out of four cases concerned patients with diagnoses other than cancer, for example, cardiovascular diseases accounting for 35% of all CDS cases.[111]

4.3. Bridging the knowledge gap in the environmental factors affecting CDS practice

Research has highlighted variations in the prevalence of CDS between countries.[103] For example, a comparative cross-country study revealed differences in CDS prevalence across European countries, ranging from 2.1% in Denmark to 8.5% in Italy.[113] Cultural and religious contexts were suggested to contribute to the higher prevalence in Italy and Belgium.[113,114] Additionally, variations in CDS practice have been identified in different care settings across and within countries, including hospitals, palliative care units, nursing homes, hospices, and home settings.[112,115] The international UNBIASED Study demonstrated varying approaches to CDS induction, with rapid induction being more common in the Netherlands and Belgium, while proportional induction was the norm in the United Kingdom.[116–119] These differences were attributed to national cultures, legal frameworks, and ethical considerations.

To explain these CDS variations, research has extensively examined the underlying factors affecting CDS practices. Several factors have been identified that influence CDS practice.[120] Clinical factors –e.g., cancer, dyspnea, and psycho-existential suffering- have mainly been associated with an increased probability of CDS administration.[120–122] Additionally, studies have found that interpersonal factors can play a role as well in CDS variations, with male patients, younger patients, and those treated by physicians who hold secular beliefs and/or supportive attitudes towards assisted dying being more likely to receive CDS.[112,123] While the literature has extensively explored such clinical and interpersonal factors, limited attention has been given to the influence of environmental factors on CDS practice. This is rather noteworthy, considering that research scholars have emphasized the potential influence of these factors.[102,103,112–115,124] This dissertation aims to contribute to this issue.

4.4. Unlocking the potential for improvement through control measures

As with assisted dying practice, research has demonstrated that specific problems, challenges, and hazards can also characterize CDS practice.[28] Consequently, discussions have arisen in the literature and the medical field regarding the circumstances under which CDS can be performed and how it should be done.[28] More specifically, the difficulties, challenges, and hazards are relating to practices in which, for example,

- physicians intentionally use CDS to shorten or terminate a patient's life (this goes against guidelines);
- relatives exert pressure on HCPs to hasten the death of deeply sedated patients;
- HCPs face ethical dilemmas when making decisions regarding CDS;
- suboptimal drugs are used for the administration of CDS;
- the assessment of medical indications is performed inaccurately or improperly;
- HCPs experience 'sedation-related emotional burden';
- HCPs struggle to distinguish between CDS and euthanasia;
- HCPs find it impossible to accurately predict the exact life expectancy of patients;
- nurses initiate CDS in the absence of physicians –which goes against guidelines-;
- the duration of CDS stresses the relatives of the patient;
- HCPs are uncertain about their specific roles during the administration and monitoring of CDS;
- HCPs lack knowledge and training regarding CDS;
- refractory symptoms are difficult to assess;
- CDS is initiated too early or too late;

- incorrect dosages of sedatives are used;
- the patient regain consciousness due to inadequate monitoring;
- and relatives are not involved in the decision-making of CDS.[101,104,118,120,125–130]

Scholars have emphasized the need to improve CDS practice in response to these problems, challenges, and hazards.[131,132] This has led to extensive debates surrounding CDS practice involving numerous practice recommendations along with the development of quality improvement initiatives.[131–134] In this regard, some authors have suggested implementing control practices, also called control measures, for CDS to improve the practice.[28,131,135–137] As mentioned earlier, control measures aim to control, manage, or regulate specific goals or objectives to ensure that individuals or processes align with predefined criteria. Thus, they can encompass nonmedical interventions, actions, and solutions aimed at preventing, mitigating, and eliminating identified hazards and reducing exposure to them.[138] For example, peer consultation is considered a proper control measure to prevent inappropriate assessment of medical indications to initiate CDS, according to the European Association for Palliative Care and various guidelines.[105,110] However, we lack clear guidance on possible control measures that could enhance CDS practice. This dissertation aims to contribute to this issue. Drawing parallels with euthanasia practice, we will initially examine their views on peer consultation for CDS and registration of CDS as possible control measures. Additionally, next to peer consultation and registration, we will also explore other possible measures they believe that could improve CDS practice.

Research questions

To address the knowledge gaps outlined in the 'Background', this dissertation has two aims, each comprising specific research questions.

The first aim is to describe current practices of control and support in euthanasia and to explore their potential for improvement in Flanders and Brussels, Belgium. To that end, we will answer the following research questions:

1. A) What are the characteristics and outcomes of peer consultations for a euthanasia request assessment, as reported by attending physicians?

   B) What are the influences of these characteristics and outcomes of peer consultations on the performance of euthanasia, as reported by attending physicians?
2. What are the (quality) characteristics of peer consultations for euthanasia request assessments, and changes over time in these characteristics, as reported by trained euthanasia (LEIF) consultants?
3. What support needs do patients requesting euthanasia and their relatives experience throughout their euthanasia trajectories?
4. Which good practices do healthcare professionals deploy in euthanasia practice?

The second aim is to describe current practices of control and support in continuous deep sedation until death and to explore their potential for improvement in Belgium. To that end, we will answer the following research questions:

5. How do physicians frame control measures for continuous deep sedation until death?
6. What are physicians' experiences and perceptions of environmental factors affecting their practices of continuous deep sedation until death?

Methods

In the following sections, we will discuss the four studies conducted to answer the aforementioned research questions. These studies reflect four different data collections using either a quantitative or qualitative research design. A quantitative research design was used to address research questions 1 and 2, while a qualitative research design was used to address research questions 3, 4, 5, and 6. In the studies on euthanasia (first dissertation aim), we studied data from Flanders and Brussels, the Dutch-speaking part of Belgium. In the studies on continuous deep sedation until death (CDS) (second dissertation aim), we studied data from Belgium.

Based on the definition in the Belgian Act on Euthanasia, euthanasia is conceptualized in this dissertation as intentionally ending the life of a person by a physician administrating lethal medication at the person's explicit and voluntary request.[31,46] On the other hand, CDS is conceptualized in this dissertation as intentionally administering sedative drugs to a person, resulting in a continuous reduction of their consciousness until death in order to alleviate the unbearable suffering from refractory symptoms.[104]

1. Life End Information Forum Study: cross-sectional survey studies among attending physicians and LEIF consultants

To address the first research question of this dissertation, we performed a cross-sectional survey study in Flanders and Brussel, Belgium, among attending physicians who 1) assessed a euthanasia request in the year prior to the survey, and 2) consulted with a LEIF consultant as the legally required second or third physician to obtain their advice on the patient's eligibility for euthanasia. Eligible participants were identified through the central LEIF database, which records such peer consultations in which attending physicians seek reimbursement from the Belgian National Institute for Health and Disability Insurance (NIHDI). For this reimbursement, the LEIF consultant must have obtained prior licensing from the NIHDI. In total, 903 attending physicians were identified as eligible. We used Dillman's Total Design Method, sending the questionnaires to the work addresses of eligible participants with up to three reminders for non-responders at 14-day intervals.[139] Data were collected from September 2019 to May 2020. Participants could complete the four-page questionnaire on paper or online (LimeSurvey). The questionnaire was similar to the one used in a previous study,[140] and covered three main topics: 1) the attending physician's sociodemographic characteristics and experiences with palliative and end-of-life care, 2) the characteristics of the attending physician's most recent peer consultation with a LEIF consultant for a euthanasia request assessment in the 12 months prior to completing the questionnaire, and 3) the attending physician's attitudes toward consulting a LEIF consultant for a euthanasia request assessment. We used closed questions to measure the outcomes of the peer consultation, namely, the LEIF consultant's advice on the patient's eligibility for euthanasia and whether euthanasia was performed or not. The answer options for the LEIF consultant's advice were: 1) 'The LEIF consultant gave the positive advice in that substantive requirements were met', 2) 'The LEIF consultant gave the negative advice in that substantive requirements were not met', and 3) 'The LEIF consultant did not formulate an advice'. The answer options for whether euthanasia was performed were: 1) 'Yes, I carried out the euthanasia', 2) 'No, I rejected the euthanasia request', 3) 'No, the patient had withdrawn the request', 4) 'No, the patient had died before the performance', 5) Yes, the LEIF consultant carried out the euthanasia, and 6) Yes, another physician carried out the euthanasia. To examine the characteristics of the peer consultations, we performed descriptive analyses. To examine the influence of these characteristics on the performance of euthanasia, we performed univariable logistic regression analyses. The dependent variable euthanasia being performed' was based on the survey question 'Did you carry out the assisted dying following the peer consultation?' The responses to this question were dichotomized into ' euthanasia not being performed' (including 'No, I rejected the assisted dying request', 'No, the patient had withdrawn the request', and "No, the patient had died before the performance') and ' euthanasia being performed' (including 'Yes, I carried out the euthanasia', 'No, the LEIF consultant carried out the euthanasia ', and 'Yes, another physician carried out the euthanasia '). More details on the methods of this cross-sectional survey study are provided in Chapter 2.

To address the second research question of this dissertation, we conducted repeated cross-sectional survey studies among LEIF consultants in Flanders and Brussels, Belgium. In the first survey study, data were collected from May to September 2008.[141] The questionnaire was sent to all LEIF consultants in Flanders and Brussels who 1) had completed at least two out of five LEIF training modules as LEIF considered this as the minimum training for delivering quality consultation, and 2) had been registered in the LEIF database as an active consultant, which meant they were available to perform LEIF consultations. 128 LEIF consultants were identified as eligible for study inclusion by using the central LEIF database. In the second survey study, we collected data from September 2019 to May 2020. The questionnaire was sent to all active LEIF consultants because the central LEIF database no longer contained updated information on the completed modules of LEIF consultants. We identified 400 LEIF consultants as eligible for study inclusion. LEIF consultants with less than two modules and an unknown number of modules (the questionnaire contained a specific question about the number of modules followed) were excluded from the 2019 study sample to ensure a valid comparison with the 2008 study sample. In both years, we used Dillman's Total Design Method, sending the questionnaires to the work addresses of eligible participants with up to three reminders for non-responders at a 14-day interval. The questionnaire collected information on: 1) the LEIF consultant's sociodemographic characteristics, professional background, and experience with palliative and end-of-life care; 2) the activities concerning euthanasia request assessments in the 12 months prior to completing the questionnaire; and 3) characteristics of the most recent euthanasia request assessment, such as characteristics of the attending physician, the patients, and the consultation process. The latter included questions regarding quality criteria for consultation informed by 1) the legal requirements for consultation in Belgian euthanasia legislation, and 2) quality criteria from previous research and taught in the LEIF training.[94,140,142,143] Participants could complete the questionnaire on paper, and in 2019, also online through LimeSurvey. With the latter option, we intended to improve the response rate. We carried out descriptive analyses to examine peer consultations' (quality) characteristics for euthanasia request assessments. To identify changes in these characteristics over time (between 2008 and 2019), we performed Fisher's exact tests (2×2 table), Fisher-Freeman-Halton exact tests (2×3 table), and Pearson χ^2 tests. More details on the methods of this repeated cross-sectional survey study are provided in Chapter 3.

As concerns ethical considerations for the LEIF study, each participant was assigned a unique ID code to enable follow-up of responses and ensure anonymity. The study and its materials were approved by the Medical Ethics Committee of the University Hospital of Brussels and the Vrije Universiteit Brussel (BUN 143201939962; March 24, 2019). In a cover letter, participants were provided with information about the study's aim and design. Informed consent was assumed upon the return of the postal questionnaire, while explicit informed consent was requested for the online questionnaire.

2. Support Needs Study: a qualitative study with patients requesting euthanasia and their relatives using semi-structured interviews and written narratives

To answer the third research question of this dissertation, we conducted an explorative, qualitative study in Flanders and Brussels, Belgium, using 1) semi-structured interviews with patients requesting euthanasia and their relatives, and 2) personally written narratives of patients requesting euthanasia through qualitative questionnaires. We purposefully chose to include personally written narratives as a data collection method for patients requesting euthanasia, as we anticipated that some patients might be reluctant or unable to participate in a semi-structured interview due to health reasons. In this way, we intended to increase the probability of including these patients and mitigate potential selection bias. Previous research has demonstrated that personally written narratives can be an effective research method for collecting data from challenging populations.[144–148]

As concerns the ontology and epistemology of this study, we adopted a social constructionist paradigm.[149] More specifically, we viewed patients and relatives as individuals who actively construe and give meaning to the support needs experienced throughout the euthanasia trajectories. We presumed that these support needs are social constructs reflecting multiple subjective realities rather than one single objective reality.[149]

With regard to patients requesting euthanasia, the eligibility criteria for study inclusion were: 1) either having expressed a desire for euthanasia to their relatives –i.e., friends or family members- or their HCPs, or having made a formal euthanasia request to their attending physician, or having received the formal approval for receiving euthanasia from their attending physician, 2) being comfortable with being interviewed in Dutch, 3) residence in Flanders or Brussels, Belgium, 4) being 18 years or older, and 5) having given informed consent to participate in the study. With regard to relatives of patients requesting euthanasia, the eligibility criteria for study inclusion were: 1) being a friend or family member of a person who either has expressed a desire for euthanasia to friends or HCPs, or has formally requested euthanasia to their attending physician, or has obtained the formal approval for receiving euthanasia from their attending physician, or received euthanasia between three months and three years prior to the interview, 2) fluency in Dutch, 3) residence in Flanders or Brussels, Belgium, 4) being 18 years or older, and 5) having given informed consent to participate in the study.

For recruiting participants, we applied purposive and snowball sampling. As regards purposive sampling, we aimed to recruit a heterogeneous study sample in terms of sociodemographic characteristics, health conditions, and the principal care setting in the case of patient participants. The recruitment occurred through healthcare and patient organizations and associations, stakeholders, and the professional network of the End-of-Life Care Research Group in Flanders, Belgium. As regards snowball sampling, participants were requested to identify potential participants who were subsequently invited to participate in the study. Those interested in study participation could contact the research team or register on a website and were then screened for study eligibility.

Patient participants were allowed to participate by means of a semi-structured interview or a personally written narrative using an online qualitative questionnaire (LimeSurvey). A semi-structured interview was conducted either online via Whereby (Whereby.com) or in person at a location chosen by the interviewee. For the semi-structured interviews, we developed a semi-structured topic guided informed by research literature and the research team's experience with euthanasia research. It comprised the following topics: 1) participants' general experiences with euthanasia practice; 2) participants' experienced malpractices regarding euthanasia; 3) participants' experienced good practices regarding euthanasia; and 4) participants' experienced support needs regarding euthanasia. Interviews were recorded and transcribed verbatim by a professional transcription service. Following each interview, we made field notes to document our initial impressions of the participant's support needs regarding euthanasia. Eligible patients who preferred study participation through a written narrative, received a unique code to complete an online qualitative questionnaire (Limesurvey). This qualitative questionnaire included open-ended questions that aligned with the topics of the topic guide covered in the semi-structured interviews. Their written narratives were converted to transcripts similar to those of the semi-structured interviews. The data collection process was guided by the principles of inductive thematic saturation in which we considered the saturation point to be reached when there were no other emergent meanings related to the identified themes of support needs.[150] Between December 2021 and September 2022, we collected the data.

As concerns the data analysis, we deployed a multi-phased interpretative thematic approach.[151,152] In the first phase, we performed open, inductive coding of the full transcripts.[151] More specifically, a coding framework was created and modified as new codes emerged. In the second phase, codes with similar meanings were merged into themes.[151] In the third phase, identified themes were discussed and reviewed in multiple project group meetings with all research team members.[151] We used the software NVivo12 and our field notes to aid us in organizing codes and identifying themes. More information on the methods of this study is provided in Chapter 4.

This study was approved by The Ethics Committee of the Brussels University Hospital and the Vrije Universiteit Brussels (BUN 143202100057; September 15, 2021). In the transcripts, we used pseudonyms and removed any identifying information. All participants provided written or oral informed consent to participate in the study. Given the nature of our study, we permitted participants to have a familiar individual present during the interview as emotional support. In addition, we provided free access to psychological counseling for participants after study participation.

3. Good Practices Study: a qualitative study using semi-structured interviews, focus groups, and an expert panel with healthcare professionals

To answer the fourth research question of this dissertation, we conducted a multimethod qualitative study using semi-structured interviews, focus groups, and an expert panel with HCPs in Flanders and Brussels, Belgium.

We took on a social constructionist lens in terms of the ontology and epistemology of this study.[149] We presumed that HCPs create and assign meaning to their own good practices in euthanasia based on their lived experiences of euthanasia practice and on their social interactions with those involved, such as patients requesting euthanasia and their relatives.[149]

The specific eligibility criteria for participants were: 1) being a HCP, 2) having lived experience of euthanasia through providing care and/or support in euthanasia practice, 3) being comfortable with being interviewed in Dutch, 4) working as HCP in Flanders or Brussels (Belgium), and 5) being 18 years or older, and 6) having given informed consent to participate in the study. We added a seventh criterion for the expert panel: holding an advanced level of expertise in a specific area of euthanasia practice.

Purposive and snowball sampling was utilized to ensure a diverse sample of participants in terms of age, sex, care settings, and healthcare professions and/or specialties. Regarding the latter, we mainly targeted recruiting physicians, nurses, psychologists, and social workers. We asked participants who had participated in the study to identify other eligible participants. Participants were recruited through various channels, including mailing lists, newsletters, social media platforms of healthcare organizations, health professional associations, and the professional network of the End-of-Life Care Research Group in Flanders, Belgium.

Between January and September 2022, we collected data through semi-structured interviews and focus groups. Because of COVID-19 measures, these data were collected online by video call using Whereby (Whereby.com) and Zoom. An interview guide was used with the following topics: 1) lived experiences with euthanasia practice, 2) difficulties and challenges experienced in euthanasia practice, 3) good practices in euthanasia practice, and 4) support needs in euthanasia practice. The development of the interview guide was informed by the literature on euthanasia and the research team's expertise in euthanasia research. On June 29, 2022, we conducted an online expert panel discussion with HCPs with advanced expertise in a specific area of euthanasia. This expert panel discussion elaborated upon a focus group approach in which panel members reflected upon the preliminary results of the interviews and the focus groups and discussed their own good practices in euthanasia. All data were audio recorded and transcribed verbatim by a professional transcription service. We followed a model of inductive thematic saturation to guide the data collection process, meaning that we continued collecting data until no new themes emerged concerning identified good practices in euthanasia.[150] Field notes were taken to document notable observations and the context.

We performed an interpretative thematic analysis in several phases.[151] The first phase involved familiarizing with the data by reading the transcripts and the field notes to identify initial patterns, concepts, and meanings concerning good practices in euthanasia.[151] The second phase encompassed developing a coding frame by generating initial codes from the full transcripts.[151] The third phase entailed sorting and collating the identified codes with a similar meaning into subthemes.[151] We used the software NVivo12 to generate codes and subthemes for these three phases. The fourth phase involved connecting subthemes to create, review, and name overarching themes.[151] This was done in several project group meetings with all research team members. Chapter 5 provides a detailed description of the methods of this study.

This study was approved by the Medical Ethics Committee of the Brussels University Hospital and the Vrije Universiteit Brussel (BUN 143202100057; September 15, 2021). All participants provided written or oral informed consent to participate. In the transcripts, identifying information about participants and other individuals was removed.

4. Continuous Deep Sedation Until Death Study: a qualitative interview study with physicians

To address the fifth research question of this dissertation, we performed an explorative, qualitative interview study with physicians having lived experience with the CDS practice in Belgium. We adopted social constructionism in terms of ontology and epistemology.[149] We presumed that physicians construe and give meaning to their own CDS practices through their lived experiences and social interactions with others and that physicians' CDS practices represent multiple subjective realities rather than a single objective reality.[149]

The eligibility criteria for participants were: 1) being a physician, 2) residency in Belgium, 3) fluency in Dutch and/or French, 4) having administered CDS at least three times in the past five years prior to the interview, and 5) having given informed consent to participate in the study.

To obtain a wide range of experiences and views regarding CDS practice, we applied purposive sampling to ensure sample variability in age, sex, care setting, and medical specialism. The recruitment of participants comprised of two approaches.[153] The first approach involved randomly selecting 40 hospitals in Belgium and requesting their physicians from oncology, palliative care, intensive care unit (ICU), and geriatric departments to participate in the study using a letter of invitation by email. We selected these medical settings as they have a higher CDS prevalence than others. We used the publicly accessible databases of the NIHDI and the Flemish Agency for Care and Health to perform this random selection. Concordantly, we randomly selected 30 general practitioners practices across Belgium to recruit general practitioners. The second approach involved requesting national and regional physician organizations and associations for general practitioners and palliative care organizations to invite their members to participate. Physicians interested in study participation could register on a website. Along with purposive sampling, we also applied snowball sampling. We asked included participants to identify other eligible physicians for study participation, whom we then contacted and invited to participate in our study.

We conducted semi-structured interviews with recruited physicians from February to May 2019. Interviews were performed face-to-face at participants' professional practice. We used a semi-structured topic guide with the following topics: 1) participants' conceptualization of CDS and general experiences with CDS practice, 2) their views on control measures for CDS practice, and 3) their views on possible solutions and actions for improving CDS practice. The topic guide was informed by literature and the research team's expertise in CDS research. Interviews were recorded using digital devices and were transcribed verbatim by a professional transcription service. Data collection was informed by a model of code saturation, in which we determined the saturation point as five consecutive interviews without the emergence of codes pointing to novel meanings.[154]

We performed a qualitative framing analysis.[155,156] The aim was to identify physicians' frames inductively by constructing them from the collected data.[157,158] Generally, frames are thought patterns that individuals use to give meaning to their social context and organize their experiences.[159] We identified physicians' frames using Entman's framework, which posits that a frame or framing has four interactive elements or 'framing functions': 1) defining problems, i.e., determining what causal agents are doing with costs and benefits; 2) diagnosing causes, i.e., identifying the forces causing the problem; 3) making moral judgments, that is, evaluating causal agents and their effects; and 4) suggesting remedies, that is, offering and justifying treatments for the problems and predicting their likely effect.[160] When applied to our study, the qualitative framing analysis aimed to examine physicians' views on 1) the problems of CDS practices, 2) the causes of these problems, 3) the value judgments about these problems, and 4) the solutions and actions, for example, control measures, to tackle these problems and improve CDS practice. The qualitative framing analysis encompassed four phases.[155] In the first phase, we conducted open and line-by-line coding on the transcripts to identify categories within Entman's four framing functions.[155,156] In the second phase, we performed axial codification by merging similar codes to create topic categories for each framing function.[155] We used the software NVivo12 to generate codes and topic categories for these two phases. In the third phase, we created frames by connecting topic categories as a logical chain of frame functions.[155] In the fourth phase, the identified frames were discussed and revised in several project group meetings with all research team members.[155] More details on these methods can be found in Chapter 6.

To address the sixth research question of this dissertation –i.e., 'What are physicians' experiences and perceptions of environmental factors affecting their practices of continuous deep sedation until death?-, we performed a secondary qualitative analysis of the data from the semi-structured interviews. More specifically, elaborating upon Heaton's classification, we carried out an inside supplementary, secondary analysis.[161,162] This signifies that the same researchers conducted an in-depth analysis of a specific topic or theme that was not or only partially covered in the primary study and/or analysis.[161,162] The qualitative framing analysis revealed as a supplemental finding that physicians in our sample identified several environmental factors affecting their CDS practices. Therefore, we conducted a secondary analysis to explore these factors in depth since this topic is under-researched. A secondary analysis is deemed appropriate when the research aim is closely linked to the one addressed in the primary analysis.[163,164] In addition, a secondary analysis maximizes the use of primary data, and it is particularly valuable when recruiting participants from a challenging population, such as physicians.[162,163]

The theoretical framework of new ecology of social practice underpinned the overall secondary analysis.[165,166] As such, we viewed CDS practice as a social practice with interconnected and dynamic ecological systems at micro, meso, and macro levels.[165] The aim was to identify and situate the environmental factors of physicians' CDS practices within these ecological levels. To that end, we carried out an interpretative thematic analysis in different phases, including the full and uncoded transcripts of all semi-structured interviews, to enhance rigor and reduce the influence of the primary analysis.[151,163,167,168] In the first phase, we performed open coding of the raw data to identify the first set of codes concerning the environmental factors affecting physicians' CDS practices.[163,168] Codes with similar meanings were then categorized, resulting in a final coding frame with 42 codes. In the second phase, we grouped these 42 codes into categories that were subsequently merged into themes based on their similarities and relationships. [163,168] We identified 22 themes and situated them on the micro, meso, or macro level. We used the software NVivo12 to create codes, categories, and themes in these two phases. In the third phase, we critically discussed and refined these themes during several project group meetings, resulting in a final framework of 12 overarching themes or environmental factors impacting the CDS practices of physicians.[163,168] More details on these methods can be found in Chapter 7.

The Medical Ethics Committee of the Brussels University Hospital and the Vrije Universiteit Brussel approved this study (BUN 143201938601; January 23, 2019). In addition, we assigned pseudonyms to all respondents in the transcripts and removed any identifying information. All physicians provided written informed consent to participate in the study.

Dissertation outline

This dissertation is divided into four parts and comprises eight chapters, a list of abbreviations, English and Dutch summaries, and academic curriculum vitae. The two dissertation aims are addressed in Part II and Part III, consisting of Chapters 2-7 (Table 5). These chapters are based on articles that have been published, accepted, or submitted for publication in scientific, peer-reviewed journals.

Part I describes this dissertation's background, research questions, and methods.

Part II focuses on control and support in euthanasia, in which we investigate their current practices and potential for improvement. This part aims to answer research questions 1-4. Chapter 2 focuses on the results of the cross-sectional survey among attending physicians in Flanders and Brussels (Belgium) who consulted a LEIF consultant for a euthanasia request assessment, in which we describe the characteristics and outcomes of these peer consultations. Chapter 3 discusses the findings of the repeated cross-sectional surveys among LEIF consultants in Flanders and Brussels (2008 vs. 2019), in which we examine the changes in their practices of assessing a euthanasia request. It is important to note that in Chapters 2 and 3, we will use the term ‘assisted dying’ as the reported peer consultations with LEIF might have included euthanasia and physician-assisted suicide cases. Chapter 4 explores the support needs that patients requesting euthanasia and their relatives experience throughout their euthanasia trajectories. Chapter 5 explores the experience-based good practices that HCPs use in euthanasia.

Part III focuses on control and support in CDS, in which we examine their current practices and potential for improvement. Chapter 6 describes how physicians frame control measures for continuous deep sedation until death. Chapter 7 investigates the physicians’ experiences and perceptions of the environmental factors affecting their CDS practices.

Part IV consists of the summary of the main findings, methodological considerations, interpretation of the main findings, and implications and recommendations for practice, policy, and research.

Table 5. Dissertation chapters of the research findings (Parts II & III)

Aim	Part I: Current practices of control and support in euthanasia and their potential for improvement				Part II: Current practices of control and support in CDS and their potential for improvement	
Chapter	2	3	4	5	6	7
Practice	Euthanasia	Euthanasia	Euthanasia	Euthanasia	CDS	CDS
General focus	Control & Support	Control & Support	Support	Support	Control	Control & Support
Specific focus	Peer consultation	Peer consultation	Support Needs	Good practices	Control measures	Environmental factors
Research question	Characteristics and outcomes of peer consultations for a euthanasia request assessment, and their influence on euthanasia?	Characteristics of peer consultations for euthanasia request assessments and their changes over time?	Support needs of patients requesting euthanasia and their relatives?	Good practices of healthcare professionals in euthanasia?	Physicians' frames regarding control measures for CDS?	Environmental factors affecting the CDS practices of physicians?
Study design	Cross-sectional survey	Cross-sectional survey	Semi-structured interviews, written narratives	Semi-structured interviews, focus groups, expert panel	Semi-structured interviews	Secondary analysis of semi-structured interviews
Participants	Attending physicians	Life End Information Forum consultants	Patients requesting euthanasia and their relatives	Healthcare professionals	Physicians	Physicians
CDS: continuous deep sedation until death						

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PART II

CONTROL AND SUPPORT IN EUTHANASIA: CURRENT PRACTICES AND POTENTIAL FOR IMPROVEMENT

Chapter 2

Characteristics and outcomes of peer consultations for assisted dying request assessments: cross-sectional survey study among attending physicians

Stijn Vissers, Sigrid Dierickx, Luc Deliens, Freddy Mortier, Joachim Cohen*, Kenneth Chambaere*

*Joint final authors

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Abstract

Background: In most jurisdictions where assisted dying practices are legal, attending physicians must consult another practitioner to assess the patient's eligibility. Consequently, in some jurisdictions, they can rely on the expertise of trained assisted dying consultants (trained consultants). However, these peer consultations remain under-researched. We examined the characteristics and outcomes of peer consultations to assess an assisted dying request with trained consultants, and explore how these characteristics influence the performance of assisted dying.

Methods: We conducted a cross-sectional survey in 2019-2020 in Belgium among attending physicians who had consulted a trained consultant for an assisted dying request assessment (N=904).

Results: The valid response rate was 56% (502/903). The vast majority of attending physicians (92%) who had consulted a trained consultant were general practitioners. In more than half of the consultations (57%), the patient was diagnosed with cancer. In 66%, the patient was aged 70 or older. Reported as the patients' most important reasons to request assisted dying: suffering without prospect of improvement in 49% of the consultations, loss of dignity in 11%, pain in 9%, and tiredness of life in 9%. In the vast majority of consultations (85%), the attending physician consulted the trained consultant because of the expertise, and in nearly half of the consultations (46%) because of the independence. In more than nine out of ten consultations (91%), the consultant gave a positive advice: i.e., substantive requirements for assisted dying were met. Eight out of ten consultations were followed by assisted dying. The likelihood of assisted dying was higher in consultations in which loss of dignity, loss of independence in daily living, or general weakness or tiredness were reasons for the request.

Conclusion: Our findings indicate that the peer consultation practice with trained consultants is most often embedded in a primary care setting. Moreover, our study corroborates previous research in that assisted dying is performed relatively less frequently in patients with cancer and more often in patients with general deterioration. Our findings suggest that attending physicians hold peer consultations with trained consultants to endorse their own decision-making and to request additional support.

Introduction

In the last decade, assisted dying – i.e., intentionally assisting in ending the life of a competent person (further referred to as the 'patient') at his or her own explicit and voluntary request by means of lethal drugs – has become an increasingly prevalent practice in and across several jurisdictions.[1] Assisted dying comprises the practices of euthanasia and physician-assisted suicide (P.A.S.). In euthanasia, health practitioners themselves administer the lethal drugs. In P.A.S., health practitioners provide or prescribe the lethal drugs to patients who then self-administer them. With Spain and New Mexico (U.S.A.) being the latest jurisdictions to have enacted assisted dying legislation,[2,3] nearly 300 million people across the globe –i.e., about 4% of the world population- are currently living in jurisdictions where assisted dying is lawful.[1] That number will likely increase, since other jurisdictions are debating the enactment of assisted dying legislation – for example, Scotland and several U.S. states including Florida, New York, and Arizona.[3,4] Consequently, assisted dying has, or will, become an important part of medical practice and health care systems in these societies.

Almost all jurisdictions with assisted dying legislation have put in place legal requirements that must be properly assessed and met before assisted dying can be carried out.[1] These requirements relate to eligibility criteria for the person requesting assisted dying (such as health condition) and procedural due care criteria such as peer consultation and reporting procedures. The present study was undertaken in Belgium, where euthanasia is legally regulated while the legal status of physician-assisted suicide remains unclear. The Belgian Federal Control and Evaluation Commission for Euthanasia (FCECE) and the Belgian National Board of Physicians treat P.A.S. as a form of euthanasia under certain conditions.[5,6] The FCECE reviews physician-assisted suicide cases on the basis of the legal requirements for euthanasia cases,[6] which are listed in Box 1.

Box 1. Legal requirements stipulated in the Belgian Act on Euthanasia

The physician who performs euthanasia commits no criminal offence when s/he ensures that:

the patient has attained the age of majority or is an emancipated minor, who is legally competent and is conscious at the time of making the request;

the request is voluntary, well-considered and repeated, and is not the result of any external coercion;

the patient is in a medically futile condition of persistent and unbearable physical or psychological suffering that cannot be alleviated, resulting from a severe and incurable condition caused by illness or accident;

s/he has respected the conditions and procedures as provided in this Act on Euthanasia.

Without prejudice to any additional conditions imposed by the physician on his/her own action, before carrying out euthanasia he/she must in each case:

inform the patient about their health condition and life expectancy, and discuss with the patient his/her request for euthanasia and the possible therapeutic and palliative courses of action and their consequences. Together with the patient, the physician must come to the belief that there is no reasonable alternative to the patient’s situation and that the patient’s request is entirely voluntary;

be certain of the patient’s persistent and unbearable physical or psychological suffering and of the durable nature of his/her request. To this end, the physician has several conversations with the patient spread out over a reasonable period of time, taking into account the progress of the patient’s condition;

consult another physician about the severe and incurable nature of the condition and inform him/her about the reasons for this consultation. The physician consulted reviews the medical record, examines the patient, and must be certain of the patient’s persistent and unbearable physical or psychological suffering that cannot be alleviated. The physician consulted reports on their findings. The physician consulted must be independent of the patient as well as of the attending physician and must be competent to give an opinion about the disorder in question. The attending physician informs the patient about the results of this consultation;

if there is a nursing team that has regular contact with the patient; discuss the request of the patient with the nursing team or its members;

if the patient so desires, discuss their request with relatives appointed by the patient;

be certain that the patient has had the opportunity to discuss his/her request with the persons that s/he wanted to meet.

If the physician believes the patient is clearly not expected to die in the near future, he/she must also:

consult a second physician, a psychiatrist or a specialist in the disorder in question, and inform him/her of the reasons for such a consultation. The consulted physician reviews the medical record, examines the patient, and must ensure himself about the persistent and unbearable physical or psychological suffering that cannot be alleviated, and of the voluntary, well-considered, and repeated nature of the euthanasia request. The consulted physician reports on his/her findings. The consulted physician must be independent of the patient as well as of the physician initially consulted. The physician informs the patient about the results of this consultation;

allow at least one month between the patient’s written request and the act of euthanasia.

The patient’s request must be in writing:

The document is drawn up, dated, and signed by the patient himself/herself.

If the patient is not capable of doing this, the document is drawn up by a person designated by the patient. This person must have attained the age of majority and must not have any material interest in the death of the patient. This person indicates that the patient is incapable of formulating his/her request in writing and the reasons why. In such a case, the request is drafted in the presence of the physician whose name is mentioned on the document. This document must be annexed to the medical record.

The patient may revoke his/her request at any time, in which case the document is removed from the medical record and returned to the patient.

After performing euthanasia, the attending physician must notify the case for review to the Belgian Federal Control and Evaluation Commission for Euthanasia.

Source: *own table based on the Belgian Act on Euthanasia*[6]

Peer consultation with another independent health practitioner is a procedural requirement incorporated into nearly all assisted dying legislation.[1] This independent health practitioner, or consultant, must be a physician.[1] In some provinces in Canada, however, the consultant may also be a nurse practitioner. Although legal modalities of peer consultation differ across jurisdictions, the common principle implies that the attending health practitioner must consult with an independent peer practitioner, or consultant, who must assess the patient's eligibility for assisted dying. This results in either a positive or negative advice from the consultant: i.e., the patient is either eligible or not for assisted dying. Consequently, peer consultation represents a due care or due diligence practice to safeguard patients, since consultants may identify those persons who are not eligible for assisted dying. Therefore, peer consultation practice is also considered an essential control measure within assisted dying practice. However, in some jurisdictions – Belgium and the Netherlands, for example – attending physicians are not legally obliged to adhere to the advice of the consultant and can perform assisted dying following a negative advice. Furthermore, specialization trainings and health services have been purposely developed in various jurisdictions to support and educate consultants in assisted dying practice and assisted dying request assessments: for instance, 'Canadian Association of MAiD Assessors and Providers' (CAMAP) in Canada, 'Voluntary Assisted Dying Medical Practitioner Training' in Western Australia, 'Support and Consultation on Euthanasia in the Netherlands' (SCEN) in the Netherlands, 'Support and Consultation for End of Life in New Zealand' (SCENZ) Group, and 'Life End Information Forum'(LEIF) in Flanders and Brussels (Belgium).

Notwithstanding the acknowledged importance of consulting trained assisted dying consultants,[7] empirical evidence on this practice is rather limited. Furthermore, previous research has especially studied the practice from the consultants' accounts, and less from the attending practitioners' perspectives.[8,9] This might have led to some bias. In addition, previous research has been mainly conducted in the early-adopting jurisdictions (such as Belgium and the Netherlands) in the early years after implementing assisted dying legislation.[10–12] Therefore, the peer consultation practice can be assumed to have changed over time, as assisted dying practice has undergone some shifts as well.[13–16] Therefore, studying the current peer consultation practice, and more specifically its peer consultations, can provide various important insights. Firstly, it can indicate which attending physicians seek the support of trained assisted dying consultants and for which cases, thus revealing the support needs of attending physicians in exploring an assisted dying request. Secondly, it can shed light on how trained assisted dying consultants assess the cases for which consultation has been sought, thereby exploring the relationship between their advices and the cases. In other words, insights can be used to identify routes to improve the care and support for patients requesting assisted dying, as well as for attending physicians who consult trained consultants.

Therefore, the aim of our study was to investigate the characteristics and outcomes of peer consultations for assisted dying request assessments between attending physicians and trained assisted dying consultants, as reported by the attending physicians. More specifically, we examined the peer consultation practice with trained assisted dying consultants in Flanders and Brussels (Belgium) – i.e., Life End Information Forum (LEIF) consultants – from the perspectives of attending physicians. The research questions are the following:

1. What are the characteristics of attending physicians who hold peer consultations for assisted dying request assessments with trained assisted dying (LEIF) consultants?
2. What are the characteristics of persons requesting assisted dying and of their requests in the peer consultations for assisted dying request assessments with trained assisted dying (LEIF) consultants?
3. What are the characteristics of the peer consultations for assisted dying request assessments with trained assisted dying (LEIF) consultants?
4. What are the outcomes of the peer consultations for assisted dying request assessments with trained assisted dying (LEIF) consultants in terms of consultants' advices on substantive requirements and in terms of assisted dying being performed?
5. Which characteristics of persons requesting assisted dying, characteristics of the requests, peer consultation characteristics, and consultants' advices are associated with the performance of assisted dying?

Methods

Study design, setting, and participants

We conducted a cross-sectional survey study among attending physicians who assessed an assisted dying request in the year prior to the study and who held a peer consultation with a LEIF consultant as the legally mandatory second or third physician. A LEIF consultant is a physician who has followed the 'LEIF Physician Training'. This training consists of five modules, each lasting 5.5 hours: 1) medical end-of-life decisions, the Belgian assisted dying legislation, and the Belgian legislation on patient rights and access to palliative care,

2) the organization and functioning of LEIF, the legal context for advance directives and advance care planning, 3) ethics and the concept of mental capacity in palliative care, 4) assisted dying in practice and research, and 5) physician communication with patients, relatives of patients, and other professional caregivers in the context of end-of-life decisions.[17] LEIF consultants perform peer consultations for assisted dying request assessments only in the Dutch-speaking region of Belgium: namely, the Brussels Capital Region and Flanders. Thus, this study was carried out in a region that comprises 68% of the Belgian population. We followed the STROBE guidelines in reporting this cross-sectional study.[18]

To identify eligible participants, we used the database of the LEIF organization, in which the peer consultations and the physicians involved are registered for reimbursement from the Belgian National Institute for Health and Disability Insurance (NIHDI). Registration of peer consultation is not mandatory. A peer consultation is only registered when the LEIF consultant seeks reimbursement for the consultation performed. Furthermore, only those LEIF consultants who are licensed in advance by the NIHDI can request such reimbursement. In total, we identified 904 attending physicians as eligible for study inclusion. Eligibility was defined as having consulted a LEIF consultant in the year prior to the study. In 2019, LEIF consultants and End of Life consultants (i.e., Walloon counterparts of LEIF consultants) acted as second or third physician in 27% of the 2655 assisted dying cases reported to the FCECE.[19]

Data collection

From September 2019 to May 2020, we sent pen and paper questionnaires to the work addresses of the attending physicians following Dillman's Total Design Method.[20] This included participants receiving up to three reminders for study participation when no response was received. A duplicate of the questionnaire was included in the second reminder. Participants could answer the questionnaire either on paper (returning it in the prepaid envelope included) or online through a website developed using Limesurvey. Each participant was assigned a unique ID code to enable follow-up of responses and to ensure the participant's anonymity.

Questionnaire and main measure instruments

We used a 4-page pre-structured questionnaire similar to the one used in a previous study by Van Wesemael and colleagues conducted in 2008.[21] Minor modifications to the original questionnaire were made to adapt it to the current context of assisted dying practice. Our questionnaire included questions about 1) the attending physician's socio-demographic characteristics and experience with palliative and end-of-life care, 2) the characteristics of his or her most recent peer consultation for an assisted dying request assessment with a LEIF consultant in the 12 months prior to the study, and 3) his or her attitudes towards consulting a LEIF consultant for an assisted dying request assessment. To measure outcomes of assisted dying, close-ended questions were included on the LEIF consultant's advice of the peer consultation and whether or not assisted dying had been performed following the peer consultation.

With regard to the advice from the consultant – i.e., the outcome of the assisted dying request – the answer options consisted of: 1) The LEIF consultant gave the positive advice in that substantive requirements were met, 2) The LEIF consultant gave the negative advice in that substantive requirements were not met, and 3) The LEIF consultant did not give advice. With regard to whether assisted dying had been performed, the answer options consisted of: 1) Yes, I carried out the assisted dying, 2) No, I rejected the assisted dying request, 3) No, the patient had withdrawn the request, 4) No, the patient had died before the performance, 5) Yes, the LEIF consultant carried out the assisted dying, and 6) Yes, another physician carried out the assisted dying.

Ethical considerations

This study and its study materials were approved by the Medical Ethics Committee of the University Hospital of Brussels (B.U.N. 143201939962; March 24, 2019). The participants received information about the aim and the design of the study in a cover letter. For the postal questionnaire, informed consent was assumed upon return. For the online questionnaire, informed consent was explicitly requested.

Statistical analysis

To answer the first, second, third, and fourth research questions, we performed descriptive analyses. Descriptive summaries are presented as N (%) and percentages were rounded up. To answer the fifth research question, we performed univariable logistic regression analyses. The dependent variable 'assisted dying being performed' is based on the survey question 'Did you carry out the assisted dying following the peer consultation?' We dichotomized answer options to this question into 'assisted dying not being performed' ('No, I rejected the assisted dying request'; 'No, the patient had withdrawn the request; and 'No, the patient had died before the performance') and 'assisted dying being performed' ('Yes, I carried out the assisted dying'; 'No, the LEIF consultant carried out the assisted dying'; and 'Yes, another physician carried out the assisted dying'). Univariable odds ratios with 95% confidence intervals were calculated for: the characteristics of persons requesting assisted dying and their requests, for peer consultation characteristics (interrelationship characteristics, reason(s) for consulting a LEIF consultant, and the attending physician's attitude towards the request prior to consultation), and for LEIF consultants' advices on substantive requirements. An alpha level of p<.05 defined statistical significance. Missing data were removed from analysis (listwise). We did not apply correction for multiple testing because of the exploratory nature of this study, to avoid missing out on potentially valuable results that initially appear not significant but have research potential for future confirmatory studies.[22] Statistical analyses were performed using SPSS IBM 27.

Results

We received a response from 503 attending physicians. We excluded one physician from the study sample, as he or she had not consulted a LEIF consultant to assess an assisted dying request in the 12 months prior to the study. This results in a valid response rate of 56% (502/903).

Characteristics of attending physicians

The attending physicians were mainly men (58.8%) and general practitioners (91.6%) (Table 1). The majority of the attending physicians (57.8%) were 50 years old or older. More than three-quarters of the attending physicians had followed an additional end-of-life or palliative care training (75.9%). More specifically, about one out of ten attending physicians had completed a postgraduate interuniversity training in palliative care (12.9%) or the Life End Information Forum (LEIF) physician training (10.6%), while a small group (5.0%) had followed training in palliative care for patients with incurable illness. Nearly half of the attending physicians (46.2%) had attended study days and seminars about pain management, and two out of five (38.8%) about advance care planning. Two out of five attending physicians (42.5%) had cared for fewer than five incurably ill patients at the end of life in the year prior to the survey. The majority of attending physicians (87.2%) had already consulted a second or third physician for assessing another assisted dying request prior to the most recent assessment.

Table 1. Characteristics of attending physicians who held peer consultations for assisted dying request assessments with trained assisted dying (LEIF) consultants (N=502)

	N (%)
Sex, Male	263 (58.8)
Age	
< 40 years	109 (21.8)
40 - 49 years	102 (20.4)
50 – 59 years	125 (25.0)
≥ 60 years	164 (32.8)
Medical specialty	
General practitioner	456 (91.6)
Other medical specialist	42 (8.4)
Additional end-of-life/palliative care training*:	381 (75.9)
Postgraduate interuniversity training in palliative care	64 (12.9)
Life End Information Forum (LEIF) physician training**	53 (10.6)
Training in palliative care for patients with incurable illness§	25 (5.0)
Study days and seminars about:	
Pain management	230 (46.2)
Advance care planning	193 (38.8)
Breaking bad news	90 (18.1)
Bereavement counselling	65 (13.1)
Existential and spiritual care	36 (7.2)
Incurably ill patients at the end of life cared for in the year prior to the survey	
< 5 patients	204 (42.5)
5-9 patients	150 (31.3)
10-19 patients	95 (19.8)
≥20 patients	31 (6.5)
Consulted a second or third physician to assess another assisted dying request prior to most recent peer consultation	431 (87.2)

Percentages may not always add to 100% because of rounding.

Missing values: Sex: n=55, Age: n=2; Medical specialty: n=4; Additional end-of-life/palliative care training: n=4; Incurably ill patients at the end of life: n=22; Consulted a 2nd or 3rd physician: n=8

LEIF: Life End Information Forum

*Multiple answers were possible.

**Five-day training focusing on assisted dying, other medical practices at the end of life, and quality criteria for consultation in assessing assisted dying requests as attending physician or consultant.

§Five-day training focusing on palliative care for people with incurable illness.

Characteristics of persons requesting assisted dying and of their requests

In about half of consultations (55.5%), the patient requesting assisted dying was female. In more than half of consultations (66.1%), the patient was at least 70 years old, and the main diagnosis was cancer (56.5%) (Table 2). General deterioration was the main diagnosis in 14.8% of the consultations, and neurological disorder in 7.5%. In 4.9% of consultations, psychiatric disorder was the main diagnosis. Suffering without prospect of improvement was indicated as one of the patient's reasons for requesting assisted dying in 80.7% of consultations, general weakness or tiredness in 45%, and loss of dignity in 39.4%. In about three out of ten consultations, loss of independence (30.7%), pain (28.7%), tiredness of life (27.9%), or not wanting to be a burden on the family/environment (26.3%) was reported as one of the patient's reasons for requesting assisted dying. When it comes to the patient's most important reason for requesting assisted dying, suffering without prospect of improvement was indicated in nearly half of the consultations (49.3%). In about one out of ten consultations, loss of dignity (11.3%), pain (9.0%), or tiredness of life (9.0%) was reported as the patient's most important reason for requesting assisted dying.

Peer consultation characteristics

The attending physician knew the LEIF consultant in about nine out of ten consultations (87.7%), most frequently as a practitioner in the same region (55.9%). In a small proportion of consultations (4.1%), the LEIF consultant knew the patient (Table 3). In the vast majority of consultations (85.1%), the attending physician consulted the LEIF consultant because of his or her expertise, and in nearly half of the consultations (46.1%) because of his or her independence as second physician. In 78.6% of the consultations, the attending physician had decided to grant the request prior to the consultation, in 19.1% he or she had not made a final decision yet, and in 2.3% he or she had already decided not to grant the request. In the majority of consultations, the attending physician discussed the medical hopelessness of the case (83.9%), the unbearable nature of the suffering (70.7%), the well-considered nature of the request (69.3%), the voluntariness of the request (56.6%), or the durability of the request (55.2%). In about three out ten consultations (27.5%), the attending physician asked questions about the practical performance of assisted dying. In one-quarter of the consultations (25.9%), the attending physician requested the LEIF consultant to assist with the performance of assisted dying. In 15.3% of the consultations, the attending physician requested the LEIF consultant to carry out the assisted dying (i.e., to administer the lethal drugs).

Table 2. Characteristics of persons requesting assisted dying (patients) and of their requests (N=502)

	N (%)
CHARACTERISTICS OF PATIENTS	
Sex, Male	214 (44.5)
Age	
< 60 years	65 (13.3)
60 – 69 years	100 (20.5)
70 – 79 years	130 (26.7)
≥ 80 years	192 (39.4)
Main diagnosis	
Cancer	278 (56.5)
General deterioration	73 (14.8)
Neurological disorder*	37 (7.5)
Psychiatric disorder	24 (4.9)
Heart failure	14 (2.8)
Chronic obstructive pulmonary disease (COPD)	14 (2.8)
Other diagnosis§	52 (10.3)
CHARACTERISTICS OF REQUESTS	
Reason(s) for requesting assisted dying**	
Suffering without prospect of improvement	402 (80.7)
General weakness or tiredness	224 (45.0)
Loss of dignity	196 (39.4)
Loss of independence in daily life	153 (30.7)
Pain	143 (28.7)
Tiredness of life	139 (27.9)
Not wanting to be a burden on the family or environment	131 (26.3)
Disability	92 (18.5)
Depression	38 (7.6)
Anxiety	33 (6.6)
Fear of suffocation	27 (5.4)
Vomiting	14 (2.8)
Other reason(s)‡	24 (4.8)
Most important reason for requesting assisted dying	
Suffering without prospect of improvement	236 (49.3)
Loss of dignity	54 (11.3)
Pain	43 (9.0)
Tiredness of life	43 (9.0)
Not wanting to be a burden on the family or environment	27 (5.6)
General weakness or tiredness	23 (4.8)
Loss of independence in daily living	13 (2.7)
Disability	10 (2.1)
Anxiety	10 (2.1)

Fear of suffocation	8 (1.7)
Depression	4 (0.8)
Vomiting	0 (0.0)
Other reason	8 (1.7)
Patient made a written request	464 (95.9)

Percentages may not always add to 100% because of rounding.
Missing values: Sex: n=21; Age: n=15; Main diagnosis: n=11; Most important reason for requesting assisted dying: n=24; Patient made a written request: n=19
LEIF: Life End Information Forum
*Neurological disorder includes 'MS/ALS', 'early stage of dementia', and 'cerebrovascular accident'.
§Examples include 'dyskeratosis congenita', 'systemic scleroderma', 'gangrene', 'cervical spinal stenosis',' interstitial lung disease', 'chronic kidney disease (CKD)', and 'primary biliary cholangitis'.
**Multiple answers were possible.
‡Examples include 'fear of losing control of life', 'blindness', and 'loss of quality of life'.

Table 3. Characteristics of peer consultations for assisted dying request assessments with trained assisted dying (LEIF) consultants (N=502)

	N (%)
INTERRELATIONSHIP CHARACTERISTICS	
Attending physician-consultant relationship	
Attending physician did not know the LEIF consultant	61 (12.3)
Attending physician knew the LEIF consultant*:	436 (87.7)
As a practitioner in the same region	278 (55.9)
Because he/she had already consulted the LEIF consultant before	124 (24.9)
As a befriended colleague	75 (15.1)
Known only by name	67 (13.5)
As a colleague from the same hospital	23 (4.6)
As a colleague from the same practice	14 (2.8)
In another way**	10 (2.1)
Patient-consultant relationship	
LEIF consultant did not know the patient	466 (95.9)
LEIF consultant knew the patient as co-treating practitioner	7 (1.4)
LEIF consultant knew the patient in another way	13 (2.7)
PROCESS CHARACTERISTICS	
Reasons for consulting a trained assisted dying (LEIF) consultant*	
Expertise of the LEIF consultant as second physician	423 (85.1)
Independence of the LEIF consultant as second physician	229 (46.1)
Questions about the legal procedure	158 (31.8)
Questions about the practical performance of assisted dying	137 (27.6)
Accessibility to/availability of LEIF consultants	129 (26.0)

Complexity of the assisted dying request	120 (24.1)
To assess the own evaluation of the assisted dying request	115 (23.1)
To avoid burdening colleagues	30 (6.0)
No other second physician was known or available	18 (3.6)
Other reason(s)†	27 (5.4)
Attending physician’s attitude towards the request prior to the peer consultation	
Had decided to grant the request	383 (78.6)
Had not made a final decision yet regarding the request	93 (19.1)
Had decided to not grant the request	11 (2.3)
Topics discussed during the peer consultation*	
Medical hopelessness of the case	418 (83.9)
Unbearable nature of the patient’s suffering	352 (70.7)
Well-considered nature of the request	345 (69.3)
Voluntariness of the request	282 (56.6)
Durability of the request	275 (55.2)
Expected time frame until death	219 (44.0)
Moment of performing assisted dying	167 (33.5)
Whether it was justified to perform assisted dying in the particular case	135 (27.1)
Whether the LEIF consultant would assist in performing assisted dying	129 (25.9)
Method of carrying out assisted dying, e.g. which drugs to use	128 (25.7)
Possible alternative palliative treatments	114 (22.9)
The place where assisted dying would be carried out	103 (20.7)
The registration with the Federal Control and Evaluation Commission for Euthanasia (FCECE)	95 (19.1)
Whether the LEIF consultant would be willing to carry out the assisted death	76 (15.3)
Possible alternative curative treatments	64 (12.9)
Legal aspects	40 (8.0)
Oher topic(s)¶	10 (2.0)

Percentages may not always add to 100% because of rounding.

Missing values: Attending physician-consultant relationship: n=5; Patient-consultant relationship: n=16; Reasons for consulting a LEIF consultant: n=5; Attending physician’s attitude towards the request prior to consulting: n=16; Topics discussed during the peer consultation with the LEIF consultant: n=5.

LEIF: Life End Information Forum

*Multiple answers were possible.

**Examples include ‘as former co-student’, ‘from same palliative network’, and ‘as a lecturer’.

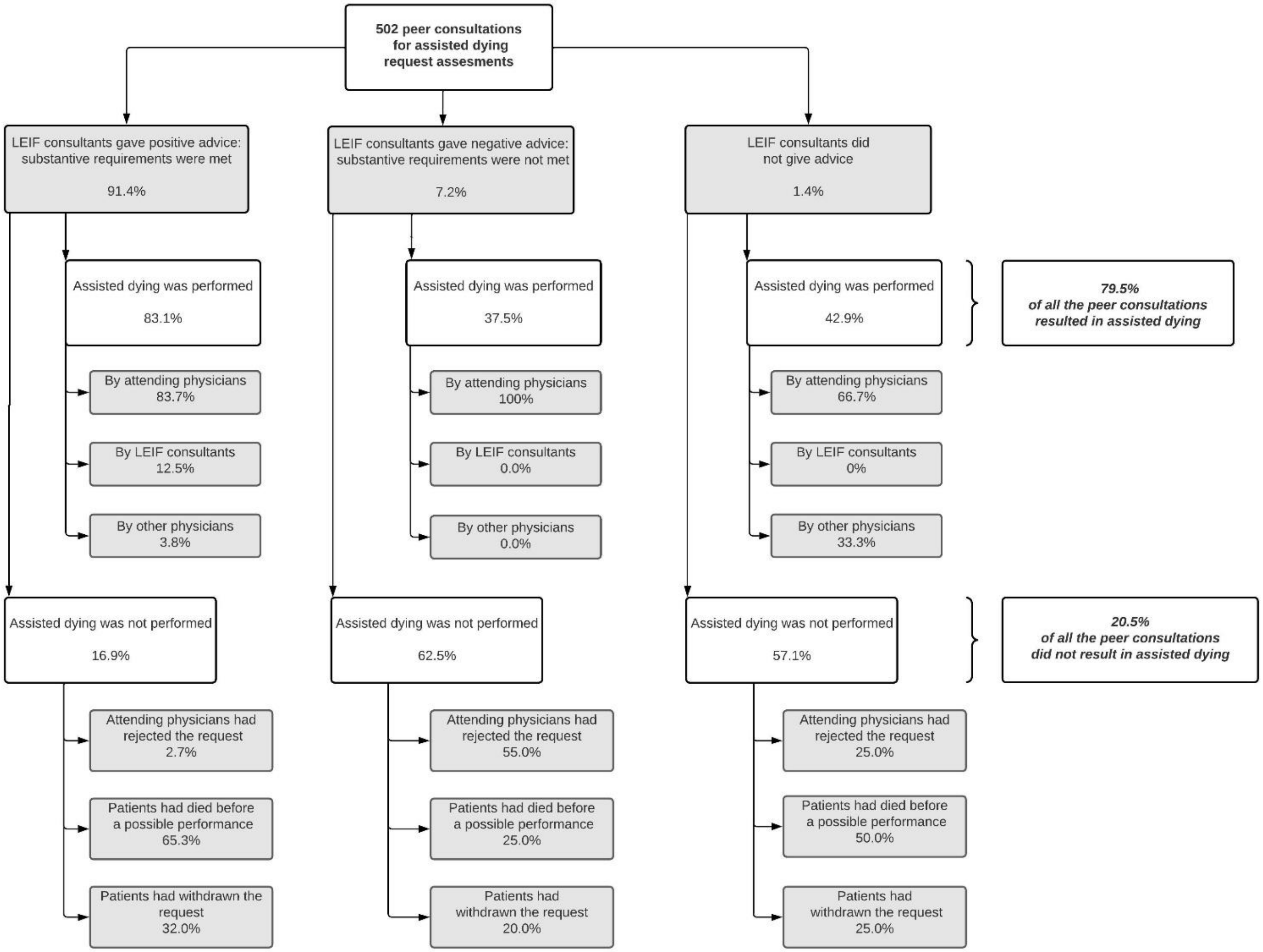
†Examples include ‘difficulties with the assisted dying procedure’, ‘LEIF consultant was a colleague’, and ‘the pressing nature of the patient's medical condition’.

¶Examples include ‘technical difficulties encountered in previous performances of assisted dying’, ‘funeral arrangement’, and ‘how to explain the eligibility of the request to the family’.

Peer advices on substantive requirements and outcomes of the assisted dying requests

The LEIF consultant gave a positive advice – i.e., substantive requirements were met – in 91.4% of the consultations, and a negative advice – i.e., substantive requirements were not met – in 7.2% (Figure 1). In 1.4% of the consultations, the LEIF consultant did not give an advice. Four out of five consultations resulted in the performance of assisted dying (79.5%). Of all the performances of assisted dying, 83.7% were carried out by the attending physician, 12.5% by the LEIF consultant, and 3.8% by another physician. One out of five consultations resulted in assisted dying not being performed (20.5%). For all cases in which assisted dying was not performed: 14.1% were because the attending physicians had rejected the request, in 56.6% the patient had died before the possible performance of assisted dying, and in 29.3% the patient had withdrawn the request.

Figure 1. Advices from life end information forum (LEIF) consultants on whether substantive requirements were met in the most recent peer consultations for an assisted dying request assessment, and the outcomes of these assisted dying requests following the consultations (within-group percentages). Missing values range from 3.0% to 3.8%. Percentages may not always add to 100% because of rounding



Characteristics of persons requesting assisted dying, characteristics of the requests, peer consultation characteristics, and peer advices associated with the performance of assisted dying

Consultations for patients with a psychiatric disorder were less likely to result in the performance of assisted dying compared to consultations for patients with cancer (47.8% vs. 81.2%, OR 0.21, 95% CI: 0.09-0.51) (Table 4). Consultations in which loss of dignity (85.2% vs. 75.6%, OR 1.86, 95% CI: 1.15-2.99), general weakness or tiredness (85.2% vs. 74.6%, OR 1.96, 95% CI: 1.23-3.12), or loss of independence in daily living (85.4% vs. 76.4%, OR 1.77, 95% CI: 1.06-2.98) was reported as one of the patient's reasons for requesting assisted dying were more likely to result in the performance of assisted dying, compared to consultations in which one of these reasons was not reported. Consultations in which depression was indicated as one of the patient's reasons for requesting assisted dying had lower odds of resulting in the performance of assisted dying (59.5% vs. 81.1%, OR 0.34, 95% CI: 0.17-0.69). Consultations in which not wanting to be a burden on the family or environment (63.0% vs. 82.0%, OR 0.37, 95% CI: 0.16-0.87) or fear of suffocation (50.0% vs. 82.0%, OR 0.22, 95% CI: 0.05-0.92) was indicated as the patient's most important reason for requesting assisted dying were less likely to lead to the performance of assisted dying, compared to consultations in which suffering without prospect of improvement was indicated as the patient's most important reason. Consultations that included questions about the practical performance of assisted dying were more likely to result in the performance of assisted dying, compared to consultations that did not include these questions (86.9% vs. 76.6%, OR 2.02, 95% CI: 1.16–3.52). Consultations in which the complexity of the assisted dying request was discussed were less likely to result in the performance of assisted dying, compared to consultations in which this was not discussed (68.4% vs. 83.0%, OR 0.44, 95% CI: 0.28%-0.71). Consultations in which the attending physician had decided to grant the request prior to consultation were more likely to result in the performance of assisted dying, compared to consultations in which the attending physician had decided not to grant the request prior to consultation (84.6% vs. 60.0%, OR 4.56, 95% CI: 1.35–15.44). Furthermore, consultations in which the LEIF consultant gave a positive advice (i.e., substantive requirements were met) were more likely to result in the performance of assisted dying, compared to consultations in which the LEIF consultant gave a negative advice (i.e., substantive requirements were not met) (83.1% vs. 37.5% OR 8.20, 95% CI: 3.84-17.49).

Table 4. Characteristics of persons requesting assisted dying (patients), characteristics of requests, peer consultation characteristics, and peer advices on substantive requirements associated with the performance of assisted dying (N=502)

	Assisted dying	
	Row %	Univariable odds ratio (95% CI)
CHARACTERISTICS OF PATIENTS AND REQUESTS		
Sex		
Male	80.1	Reference
Female	78.8	0.87 (0.55 – 1.36)
Age		
< 60 years	80.3	Reference
60 – 69 years	78.0	0.87 (0.39 – 1.91)
70 – 79 years	78.5	0.89 (0.42 – 1.90)
≥ 80 years	80.7	1.03 (0.50 – 2.12)
Main diagnosis		
Cancer	81.2	Reference
General deterioration	82.2	1.07 (0.55 – 2.10)
Neurological disorder*	80.6	0.96 (0.40 - 2.32)
Psychiatric disorder	47.8	**0.21 (0.09 – 0.51)**
Heart failure	76.9	0.77 (0.21 - 2.91)
Chronic obstructive pulmonary disease (COPD)	85.7	1.39 (0.30 – 6.43)
Other diagnosis§	78.0	0.82 (0.40 – 1.72)
Reason(s) for requesting assisted dying**		
Suffering without prospect of improvement	80.5	1.37 (0.79 – 2.36)
Loss of dignity	85.2	**1.86 (1.15 - 2.99)**
Pain	81.1	1.16 (0.71 – 1.89)
Tiredness of life	79.0	0.96 (0.59 – 1.56)
Not wanting to be a burden on the family/environment	78.3	0.91 (0.56 – 1.49)
General weakness or tiredness	85.2	**1.96 (1.23 – 3.11)**
Loss of independence in daily life	85.4	**1.77 (1.06 – 2.98)**
Disability	84.6	1.53 (0.82 – 2.83)
Anxiety	81.8	1.18 (0.47 – 2.93)
Depression	59.5	**0.34 (0.17 – 0.69)**
Fear of suffocation	81.5	1.15 (0.42 – 3.10)
Vomiting	85.7	1.57 (0.35 – 7.12)
Other reason(s)	83.3	1.31 (0.44 – 3.92)
Most important reason for requesting assisted dying		
Suffering without prospect of improvement	82.0	Reference
Loss of dignity	90.7	2.16 (0.81 – 5.74)
Pain	76.7	0.73 (0.33 – 1.59)
Tiredness of life	72.1	0.59 (0.27 – 1.20)

Not wanting to be a burden on the family/environment	63.0	**0.37 (0.16 – 0.87)**
General weakness or tiredness	82.6	1.05 (0.34 – 3.23)
Loss of independence in daily living	75.0	0.66 (0.17 – 2.54)
Disability	80.0	0.88 (0.18 – 4.29)
Anxiety	80.0	0.88 (0.18 – 4.29)
Depression	33.3	0.11 (0.01 – 1.24)
Fear of suffocation	50.0	**0.22 (0.05 – 0.92)**
Other reason	87.5	1.54 (0.18 – 12.85)
PEER CONSULTATION CHARACTERISTICS		
Attending physician-consultant relationship		
Consultant did not know the attending physician	77.6	Reference
Consultant knew the attending physician	79.7	0.71 (0.59 – 2.20)
Patient-consultant relationship		
LEIF consultant did not know the patient	79.2	Reference
LEIF consultant knew the patient‡	84.2	0.72 (0.20 – 2.50)
Reason(s) for consulting a LEIF consultant		
Expertise of the LEIF consultant as second physician	79.7	1.10 (0.60 – 2.07)
Independence of the LEIF consultant as a second physician	81.9	1.33 (0.85 – 2.08)
Questions about the legal procedure	81.5	1.21 (0.75 – 1.96)
Questions about the practical performance of assisted dying	86.9	**2.02 (1.16 – 3.52)**
Accessibility to/availability of the LEIF consultant	83.6	1.44 (0.85 – 2.44)
Complexity of the assisted dying request	68.4	**0.44 (0.28 – 0.71)**
To assess the own evaluation of the assisted dying request	77.2	0.84 (0.51 – 1.39)
To avoid the burdening of colleagues	79.3	0.99 (0.39 – 2.50)
No other second physician was known or available	88.9	2.11 (0.48 – 9.35)
Other reason(s)	85.2	1.52 (0.51 – 4.49)
Attending physician’s attitude towards the request prior to the peer consultation		
Had decided not to grant the request	60.0	Reference
Had decided to grant the request	84.6	**4.56 (1.35 – 15.44)**
Had not made a final decision yet	54.5	1.25 (0.36 – 4.41)
PEER CONSULTANTS‘ ADVICES ON SUBSTANTIVE REQUIREMENTS		
Negative advice: substantive requirements were not met	37.5	Reference
Positive advice: substantive requirements were met	83.1	**8.20 (3.84 – 17.49)**
Did not gave advice	42.9	1.25 (0.24 – 6.57)

Missing values range from 3.0% to 5.6%.
Percentages are row percentages.
Bold indicates statistical significance ($p < 0.05$).
CF: confidence interval.
*Neurological disorder includes ‘MS/ALS’, ‘early stage of dementia’, and ‘cerebrovascular accident’.
** Multiple answers were possible. Answer option ‘no’ is the reference category.
‡LEIF consultant knew the patient either as co-treating practitioner or in another way.

Discussion

Main Findings

The large majority of attending physicians consulting a trained assisted dying (LEIF) consultant for an assisted dying request assessment were general practitioners. The majority of peer consultations concerned patients with cancer, and a considerable proportion concerned patients with general deterioration. In nine out of ten peer consultations, LEIF consultants gave a positive advice – i.e., substantive requirements were met. About four out of five peer consultations resulted in the performance of assisted dying. Peer consultations in which loss of dignity, loss of independence in daily living, or general weakness or tiredness was reported as the patient's reason for requesting assisted dying were more likely to result in the performance of assisted dying. Peer consultations in which a psychiatric disorder was reported as a diagnosis were less likely to result in the performance of assisted dying.

Strengths and limitations

Our study has several strengths. First of all, it focused on describing the characteristics of peer consultations for assessing assisted dying requests, whereas other studies have mainly focused on those of the actual performance of assisted dying. This topic has been scarcely addressed in recent literature. Hence, our findings may be particularly relevant for the vast majority of jurisdictions with assisted dying legislation where peer consultation is legally required as well, such as in Canada, Spain, the Netherlands, several U.S. states, New Zealand, several Australian states, and Luxembourg. Secondly, we obtained a relatively high response rate for a physician survey study. Most likely, this stems from the robust mailing procedure and the questionnaire being available both online and on paper to reduce technical barriers. Thirdly, we only collected data on the most recent peer consultations to reduce recall bias. With regard to limitations, recall bias may be possible, especially for data on peer consultations that were carried out several months prior to the survey. Moreover, it is possible that there was some ascertainment bias, as only those peer consultations were included for which LEIF consultants requested a reimbursement from the NIHDI. Moreover, some selection bias might have occurred, as we might have obtained a higher study participation by those physicians who have a particular interest in assisted dying or who endorse the importance of peer consultation in assisted dying.

Interpretation of findings

Our findings suggest that the consultation practice with LEIF consultants is most often embedded in a specific setting – namely, in a primary care setting where both attending physicians and consultants are acquainted with each other. First of all, this is substantiated by the majority of attending physicians (92%) in our study who were general practitioners. This corroborates previous research on assisted dying request assessments by trained assisted dying consultants in Belgium and the Netherlands.[9,10,21,23,24] In a previous study, we also found that the majority of LEIF consultants (72%) were general practitioners.[17] In contrast, other studies have suggested that about 40% to 60% of assisted dying cases in Belgium are carried out by general practitioners.[25,26] Consequently, it appears that attending physicians with a medical specialty other than general medicine consult non-LEIF consultants, thereby suggesting an alternative 'circuit' of mandatory peer consultations in non-primary care settings such as hospitals. Probably, medical specialists in these settings have easier and adequate access to relevant expertise or peers to assess an assisted dying request. Future research could examine that specific peer consultation practice and whether its characteristics differ from the LEIF practice. Secondly, the specific setting of the LEIF practice is also substantiated by a high proportion of attending physicians who indicated knowing the consultant in some manner, mostly as a practitioner in the same region. Moreover, some attending physicians reported that the LEIF consultant was a befriended colleague. This could imply that they put emphasis on having a trust relationship with consultants in assisted dying practice, which can facilitate open communication and is related to better healthcare delivery and outcomes for patients.[27] Although this finding does not allow us to make sound conclusions about the legally required independence between attending physicians and consultants, it may prompt further conceptual reflection on its inherent meaning as it has not been specifically defined in Belgian assisted dying legislation. However, the FCECE interprets independence as the fact that the attending physician cannot have family or hierarchical ties with the consultant.[6]

Our study presents a broader picture of the context of peer consultations with trained assisted dying consultants by both examining attending physicians' reasons to initiate them and their outcomes. With regard to the latter, we found that the LEIF consultant gave a positive advice (i.e., the patient was eligible for assisted dying) in the vast majority of peer consultations (91%). This is more than reported by studies in the Netherlands, in which the figure is four out of five.[9] Moreover, those peer consultations with a positive advice were considerably more likely to result in assisted dying compared to consultations with a negative advice, despite the advice not being binding. The large proportion (88%) of cases in which the consultant knew the attending physician would seem a plausible reason for the large proportion of (91%)

of cases receiving a positive advice. However, such a conclusion is not warranted by the data following the fact that cases in which the consultant did not know the attending physician were not less likely to result in assisted dying compared to those in which the consultant did know the attending physician. Notwithstanding, future research could confirm that hypothesis by investigating what characteristics of peer consultations influence a positive advice. On the other hand, the large proportion of positive advices may indicate that attending physicians approach assisted dying requests with considerable due care, only contacting LEIF consultants when there is a high chance of the patient being eligible for assisted dying. This could explain our finding that more than three-quarters (79%) of attending physicians had already decided to grant the request prior to the advice. That result may also suggest that attending physicians indeed view these peer consultations as means of validating their own decision concerning the patient's eligibility, as intended by assisted dying legislation in Belgium. However, one may question the added value of peer consulting when the attending physician has already made a decision beforehand: in such cases, is the peer consultation merely a 'tick the box exercise' – i.e., merely meeting the procedural requirement to be legally compliant? Or more generally, what is the added value of peer consultation, as attending physicians are not legally obliged to adhere to the peer advice? Our findings provide more nuance to such inquiries, showing that attending physicians also approach peer consultation as an opportunity to fulfil their specific support needs regarding assisted dying. These support needs are reflected in their reasons to hold peer consultations with trained assisted dying consultants. For example, some attending physicians consulted LEIF consultants for medical-technical questions about the performance (28%), requesting assistance in the actual performance (26%), or requesting consultants to carry out the actual performance of assisted dying (15%). In fact, some LEIF consultants carried out the assisted dying following the peer consultations. Engaging trained assisted dying consultants in the performance of assisted dying might be good medical practice. Their specific expertise can be useful when attending physicians experience difficulties or challenges during the performance (for instance, finding the proper vein for injecting the lethal drugs). However, some questions can be raised as well about consultants carrying out assisted dying. Had they become the new attending physicians of the patients concerned? In this case, another independent consultant must have been consulted again in order to assess the request. Alternatively, it could be that the consultant was present during the performance and took over at the very last moment (for example, because the attending physician was ultimately not capable of performing it)? More insights into the specific context of this phenomenon are warranted. Regardless of consultants' motives for administering the lethal drugs instead of the attending physicians, the physicians involved should consider to what extent this is in line with assisted dying legislation in Belgium. Furthermore, we found that certain legal requirements were not explicitly discussed in some peer consultations: 84% discussed the medical hopelessness of the case, 71% the unbearable nature of the patient's suffering, 69% the well-considered nature of the request, 57% the voluntariness of the request, and 55% the durability of the request. Discussing all legal requirements can be viewed as a quality criterion for peer consultation in assisted dying practice.[10,17]

Lastly, our study provides a novel characterization of the patient population requesting and receiving assisted dying. Firstly, we found that persons with cancer were the largest patient group requesting assisted dying (57%). This confirms previous research.[15,26,28,29] However, the proportion of patients with cancer in our study is notably lower compared to similar studies among trained assisted dying consultants in Belgium in 2009 and in the Netherlands in 2011.[9,21] In these past studies, patients with cancer represented three-quarters of the consultations. This change might indicate that the assessments concerning patients with cancer are commonly perceived as less complex because of the predictability of the disease trajectory, and, as a result, attending physicians may feel less need to rely on the expertise of trained assisted dying consultants, and therefore consult physicians without special assisted dying training.[8] Secondly, the proportion of peer consultations concerning patients with general deterioration has increased compared to previous similar studies: from 7% then to 15% now.[21] Furthermore, cases reporting general weakness or loss of dignity as a reason for requesting assisted dying were more likely to result in the performance of assisted dying, compared to peer consultations in which these reasons were not reported. That is in line with evidence from the Netherlands[9,30], and our findings seem to confirm the trend that persons with old-age-related conditions are currently more often requesting and receiving assisted dying than in the early years of legislation.[14,17,31] This could be attributed to attending physicians being increasingly open to proceeding with such requests. However, these assessments are commonly perceived as less clear-cut and more challenging in comparison with those from patients with cancer.[8,32] Furthermore, attending physicians may feel better supported by trained assisted dying consultants, and may consult them more frequently for such cases. Thirdly, 5% of peer consultations concerned patients with psychiatric conditions and were less likely to result in the performance of assisted dying compared to those concerning patients with cancer. This is in line with Dutch studies,[23,33] and might indicate that attending physicians are willing to explore these patients' eligibility for assisted dying but are rather reluctant to carry it out afterwards.[34] It could also be that they were less willing to perform assisted dying in these patients due to a highly mediatized prosecution of physicians involved in the assisted dying case of a patient with a psychiatric condition in Flanders (Belgium) in 2020.[35] Alternatively, attending physicians may have refused to perform assisted dying due to a negative peer advice (i.e., not all substantive requirement were fulfilled – for example, because not all reasonable therapeutic options had been utilized).[36,37] Another explanation could be that assisted dying was not performed because patients with psychiatric conditions may tend to withdraw their request or put it on hold.[38,39] Thus, our findings suggest that attending physicians may consider reasons related to psychological dimensions of suffering – e.g., loss of dignity, general weakness, and loss of independence – as compelling for granting assisted dying, but they may approach 'psychological reasons' differently in patients with psychiatric conditions. In other words, differences in medical diagnosis between patient groups might explain differences in receiving assisted dying.

Conclusion

Examining peer consultations for assisted dying request assessments provides important insights into assisted dying practices, as it sheds light on the dynamics prior to performance. Our findings indicate that the peer consultation practice with trained assisted dying consultants is most often embedded in a primary care setting. Moreover, our study corroborates previous research in that an increasing proportion of assisted dying consultations concerns patients with general deterioration, whereas in earlier periods after the implementation of the assisted dying law this most often concerned patients with cancer. Attending physicians seem to hold peer consultations to validate their own decision-making and to request additional support, especially in relation to the actual performance. Therefore, support in assisted dying should be aligned with the challenges of current practice, while paying particular attention to the preparation for, and the act of, performance in order to adequately meet the needs of attending physicians.

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Chapter 3

Assisted dying request assessments by trained consultants: changes in practice and quality - Repeated cross- sectional surveys (2008–2019)

Stijn Vissers*, Sigrid Dierickx*, Kenneth Chambaere, Luc Deliens, Freddy Mortier, Joachim Cohen

*Joint first authors

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Abstract

Objectives: To study changes in the peer consultation practice of assessing assisted dying requests and its quality among trained 'Life End Information Forum' (LEIF) consultants in Belgium between 2008 and 2019.

Methods: Cross-sectional surveys conducted in 2008 (N=132) and 2019 (N=527) among all registered LEIF consultants.

Results: The response rate was 75% in 2008 and 57% in 2019. In 2019 compared to 2008, more LEIF consultants were significantly less than 40 years old (25% / 10%, p=.006) and at least 60 years old (34% / 20%, p=.006). In their activities regarding assessments of assisted dying requests over 12 months, we found a significant decrease in the number of patients who did not meet the substantive requirements for assisted dying in 2019 compared to 2008 (1-4 patients: 41% / 58.8%, p=.02). In their most recent assessments of an assisted dying request, LEIF consultants in 2019 made significantly more assessments of patients aged 80 years or older than in 2008 (31% / 9%, p<.001), and significantly fewer assessments for patients with cancer (53% / 70%, p=.034). Regarding adherence to quality criteria for consultation, LEIF consultants discussed unbearable suffering (87% / 65%, p=.003) and alternative treatments (palliative: 48% / 13%, p<.001; curative: 28% / 5%, p=.002) significantly more often with the attending physician.

Conclusion: Changes in peer consultation practice and its quality among LEIF consultants likely reflect changes in assisted dying practice in general, as well as changes in LEIF consultations on more complex cases for which LEIF consultants' expertise is required.

Introduction

Assisted dying, i.e. euthanasia and physician-assisted suicide, means the practices of intentionally and actively ending patients' lives at their own request, by medical means, with the assistance of health practitioners.[1] Legal access to assisted dying is growing worldwide as several jurisdictions have recently legalized the practice, e.g. Canada, Western Australia and Spain. At present, jurisdictions allowing assisted dying are home to approximately 250 million people, a number that will probably increase in the near future as other jurisdictions such as Austria and Queensland (Australia) are currently drafting assisted dying legislation.

In all jurisdictions, assisted dying is legally subject to substantive and procedural requirements, also known as due care requirements or legal safeguards. Substantive requirements are the eligibility criteria that a person must meet to receive assisted dying, while procedural requirements are the procedures that attending health practitioners must satisfy before and after providing assisted dying.[2] Peer consultation is one of the procedural requirements implemented in most assisted dying legislation.[1] It implies that the attending health practitioner is legally obliged to consult another independent health practitioner – i.e. the peer consultant – before performing assisted dying.[3] The peer consultant must assess whether the assisted dying request meets the substantive requirements. As such, peer consultation constitutes a control measure and safeguards the patient, as the consultant's assessment may reverse an erroneous assessment made by the attending health practitioner.[4] However, some assisted dying legislations do not require the attending health practitioner to comply with the consultant's assessment. In Belgium and the Netherlands, for example, the attending physician is required to append the consultant's report to their notification of the assisted dying case to the review committee, but s/he is not required to follow the consultant's advice.[2]

Specialisation training and/or health services have been established in several jurisdictions to educate and guide peer consultants in assessing assisted dying requests, such as the 'Canadian Association of MAiD Assessors and Providers' (CAMAP) in Canada, 'Voluntary Assisted Dying Medical Practitioner Training' in Western Australia, 'Support and Consultation on Euthanasia in the Netherlands' (SCEN) in the Netherlands, and 'Life End Information Forum' (LEIF) in Flanders and Brussels (Belgium). These organisations are based on the vision that comprehensive expertise and skills in assisted dying and palliative care are needed to ensure the quality of peer consultation practice, and thereby the quality of assisted dying practice.[2] Therefore, some jurisdictions view specialized training of consultants as a safeguard in itself, such as

Western Australia, where consultants are legally obliged to complete specialized training before assessing assisted dying requests.[5] Internationally, the role of governments varies somewhat in the implementation, support and quality assurance of these services. In Belgium, for example, the role of the government is rather limited in the implementation of and the support for LEIF as health service organization. LEIF was originally founded by palliative care professionals and the Right to Die with Dignity Association in 2003, one year after the assisted dying legislation was brought into force. It functions as an self-governing and self-supporting organization. Consequently, the quality assurance of their services and training falls under its own responsibility. Since 2015, the Belgian National Institute for Health and Disability Insurance (NIHDI) compensates accredited LEIF consultants who assess an assisted dying request as the legally required second or third physician.

In Belgium, the assisted dying legislation stipulates that only physicians may assess assisted dying requests and perform assisted dying (Table 1).[6] Peer consultation physicians trained by LEIF, i.e. LEIF consultants, were studied in the years following implementation of LEIF in 2003. Research showed that LEIF consultants contributed to the quality of peer consultation for assisted dying requests. [7–13] Nevertheless, room for improvement was also found, particularly regarding consultants' compliance with the procedural requirements of assisted dying legislation, such as independence from the patient and examining the patient.[10,11]

Given this room for improvement, insights are needed into how peer consultation has changed. That said, we can assert that some changes in practice have occurred. The number of trained consultants and their characteristics have likely changed due to late adopters joining LEIF. Moreover, the quality of peer consultation may have changed as trained consultants can be assumed to become better acquainted with assisted dying over time. Furthermore, changes in assisted dying practice may have provoked changes in peer consultation practice. More specifically, the patient population requesting assisted dying in Belgium has changed substantially over time, resulting in more requests related to non-terminal disorders and multimorbidity.[14,15] This change has undoubtedly made assisted dying decision-making more complex, suggesting that attending health practitioners may feel a greater need to engage with trained consultants who have a particular understanding of such complex cases.

Table 1. Legal requirements stipulated in the Belgian Act on Euthanasia

The physician who performs euthanasia commits no criminal offence when s/he ensures that:

the patient has attained the age of majority or is an emancipated minor, who is legally competent and is conscious at the time of making the request;

the request is voluntary, well-considered and repeated, and is not the result of any external coercion;

the patient is in a medically futile condition of persistent and unbearable physical or psychological suffering that cannot be alleviated, resulting from a severe and incurable condition caused by illness or accident;

s/he has respected the conditions and procedures as provided in this Act on Euthanasia.

Without prejudice to any additional conditions imposed by the physician on his/her own action, before carrying out euthanasia he/she must in each case:

inform the patient about their health condition and life expectancy, and discuss with the patient his/her request for euthanasia and the possible therapeutic and palliative courses of action and their consequences. Together with the patient, the physician must come to the belief that there is no reasonable alternative to the patient's situation and that the patient's request is entirely voluntary;

be certain of the patient's persistent and unbearable physical or psychological suffering and of the durable nature of his/her request. To this end, the physician has several conversations with the patient spread out over a reasonable period of time, taking into account the progress of the patient's condition;

consult another physician about the severe and incurable nature of the condition and inform him/her about the reasons for this consultation. The physician consulted reviews the medical record, examines the patient, and must be certain of the patient's persistent and unbearable physical or psychological suffering that cannot be alleviated. The physician consulted reports on their findings. The physician consulted must be independent of the patient as well as of the attending physician and must be competent to give an opinion about the disorder in question. The attending physician informs the patient about the results of this consultation;

if there is a nursing team that has regular contact with the patient; discuss the request of the patient with the nursing team or its members;

if the patient so desires, discuss their request with relatives appointed by the patient;

be certain that the patient has had the opportunity to discuss his/her request with the persons that s/he wanted to meet.
If the physician believes the patient is clearly not expected to die in the near future, he/she must also:
consult a second physician, a psychiatrist or a specialist in the disorder in question, and inform him/her of the reasons for such a consultation. The consulted physician reviews the medical record, examines the patient, and must ensure himself about the persistent and unbearable physical or psychological suffering that cannot be alleviated, and of the voluntary, well-considered, and repeated nature of the euthanasia request. The consulted physician reports on his/her findings. The consulted physician must be independent of the patient as well as of the physician initially consulted. The physician informs the patient about the results of this consultation;
allow at least one month between the patient’s written request and the act of euthanasia.
The patient’s request must be in writing:
The document is drawn up, dated, and signed by the patient himself/herself.
If the patient is not capable of doing this, the document is drawn up by a person designated by the patient. This person must have attained the age of majority and must not have any material interest in the death of the patient. This person indicates that the patient is incapable of formulating his/her request in writing and the reasons why. In such a case, the request is drafted in the presence of the physician whose name is mentioned on the document. This document must be annexed to the medical record. The patient may revoke his/her request at any time, in which case the document is removed from the medical record and returned to the patient.
After performing euthanasia, the attending physician must notify the case for review to the Belgian Federal Control and Evaluation Commission for Euthanasia.
<u>Source:</u> *own table based on the Belgian Act on Euthanasia*[6]

Therefore, the present study reports on the changes over time in peer consultation and its quality by LEIF consultants. Previous research concentrated on the reports of attending health practitioners on assisted dying practice.[14,16,17] By studying peer consultation from the perspective of trained consultants, this study contributes to a better understanding of the assisted dying practice. Findings may be instructive for other jurisdictions on how the peer consultation practice of assessing assisted dying requests and its inherent quality may change over time. Hence, findings may help other jurisdictions to anticipate potential changes in the practice and its quality, and to improve both. We address the following research questions:

1. What changes occurred between 2008 and 2019 in the number, characteristics, and end-of-life care experiences of LEIF consultants?
2. What changes occurred between 2008 and 2019 in the case characteristics and outcomes of LEIF consultants' activities regarding assessing assisted dying requests over a 12-month period?
3. What changes occurred between 2008 and 2019 in adherence to quality criteria for consultation of LEIF consultants' most recent case?

METHODS

Setting

LEIF is a health service organization providing 'LEIF Physician Training' to Dutch-speaking physicians in Flanders and Brussels. These two regions are home to 68% of the Belgian population. The training focuses on assisted dying, other medical practices at the end of life and quality criteria for consultation in assessing assisted dying requests as the attending physician or consultant. The topics are taught in-person by experts in palliative care and assisted dying in five modules, each lasting 5.5 hours. These five modules focus on 1) medical end-of-life decisions, the Belgian assisted dying legislation, and the Belgian legislation on patient rights and access to palliative care, 2) the organization and functioning of LEIF, the legal context for advance directives, and advance care planning, 3) ethics and the concept of mental capacity in palliative care, 4) assisted dying in practice and research, and 5) physician communication with patients, relatives of patients, and other professional caregivers in the context of end-of-life decisions. Physicians obtain the 'LEIF consultant' or 'LEIF physician' qualification when they have completed the first two modules. This is the core curriculum of the training, because LEIF considers the topics discussed in these modules as the minimum standard to ensure quality in peer consultations and assisted dying. However, LEIF encourages physicians to complete all modules of the LEIF training. These LEIF consultants can be contacted by LEIF or health practitioners to 1) formally assess an assisted dying request as an independent consultant, or 2) provide advice or information on medical practices at the end of life, e.g. assisted dying or palliative sedation. LEIF consultants can also carry out other activities, such as giving information about end-of-life matters to patients and their relatives.

Study design, participants, and data collection

We report on the results of two cross-sectional studies conducted in 2008 and 2019 among LEIF consultants.[13] We identified participants using LEIF's database of all trained physicians. Access to the LEIF database was provided by the central management of LEIF. In 2008, the survey was sent to all LEIF consultants in Flanders and Brussels who had completed at least two modules of the LEIF training and were active, i.e. registered in the LEIF database as available to perform LEIF consultations (N=132) (Figure 1). Four physicians were later excluded from the study sample as they indicated that they were no longer active as LEIF consultants. In 2019, the questionnaire was sent to all active LEIF consultants (N=527), as information on the number of completed modules was no longer available. Of the 527 physicians who were sent the questionnaire, 127 were excluded from the study sample. The main reason for exclusion was the physician indicating they were no long active as a LEIF consultant (N=66). Furthermore, we excluded physicians who followed less than two modules of the LEIF training (N=19) or who did not indicate the amount of modules followed (N=2).

Data were collected from May to September 2008 and September 2019 to May 2020. LEIF consultants received a questionnaire, cover letter and prepaid return envelope. To increase response rate, respondents were able to complete the questionnaire on paper or digitally (using Lime Survey on a specially designed website). We designed an intensive follow-up mailing in accordance with the Total Design Method.[18] In case of non-response, LEIF consultants received a maximum of three reminders at 14-day intervals. The second reminder included a duplicate of the questionnaire to anticipate the potential loss of the original. A non-response survey was sent to LEIF consultants who had not completed the questionnaire after three reminders.

A unique ID number was allocated to each LEIF consultant to guarantee complete anonymity of the respondents and enable follow-up on responses. This ID number furthermore allowed consultants to access the online questionnaire. Thus the researchers were unable to link the LEIF consultants' identity to the data.

Questionnaire

The pre-structured questionnaire asked about 1) LEIF consultants' socio-demographic characteristics, professional background and overall expertise and experience in palliative and end-of-life care; 2) their activities as LEIF consultants for assisted dying requests in the 12 months prior to completing the questionnaire; and 3) characteristics of the attending physician, patient, and consultation process in the most recent case where the LEIF consultant had assessed an assisted dying request. Questions on quality criteria for consultation were included, based on 1) the substantive and procedural requirements for consultation in Belgian assisted dying legislation (see Table 1), and 2) criteria proposed by previous research [4,8,10,11] and taught in the LEIF Physician Training.

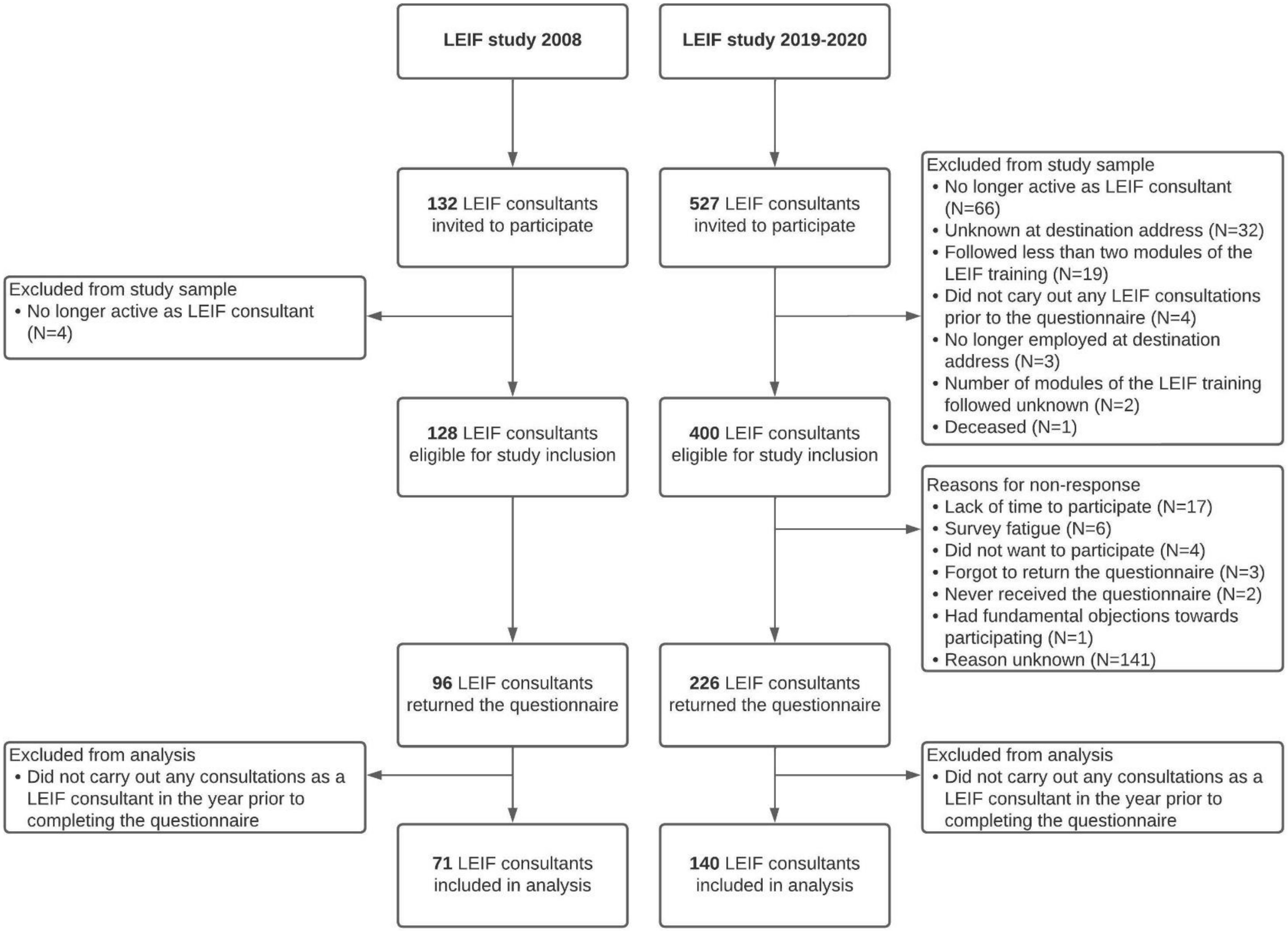
Statistical analyses

For analyses relating to the first research question, only data from respondents in 2008 and 2019 who had carried out at least one consultation as a LEIF consultant – in the context of assisted dying or any other medical end-of-life practice – in the year prior to completing the questionnaire were used. For analyses relating to the second, third and fourth research question, we used data from respondents in 2008 and 2019 who had formally assessed at least one assisted dying request as a legally required independent consultant. We used Fisher's exact tests (2 x 2 table), Fisher-Freeman-Halton exact tests (2 x 3 table), and Pearson chi-square tests to identify changes between 2008 and 2019 in characteristics of LEIF consultants and LEIF consultants' activities as mandatory consultants in assisted dying requests. Missing data were removed from the analysis (listwise). Statistical analyses were performed using SPSS IBM 26.

Results

Responses were received from 226 LEIF consultants in 2019, resulting in a valid response rate of 57% (226/400), compared with 75% (96/128) in 2008 (Figure 1).[13] Analysis of non-response questionnaires revealed lack of time as the most quoted reason for non-participation in 2019. A non-response survey was not conducted in 2008.

Figure 1. Participant flow chart. A non-response survey was only conducted in the 2019 study. (LEIF: Life End Information Forum)



Number, characteristics, and end-of-life care experiences of LEIF consultants

The number of LEIF consultants rose from 128 in 2008 to 400 in 2019. Compared with those in 2008, more LEIF consultants in 2019 were significantly less than 40 years old (25% / 9.9%, p=.006) and at least 60 years old (34.3% / 19.7%, p=.001) (Table 2). Their medical specialty did not change significantly, with LEIF consultants still being primarily general practitioners (73.2% / 72.1%). In 2019, the majority of LEIF consultants had worked as such for less than five years (43.6%) or five to nine years (30.8%). In 2019, LEIF consultants' main motivation to pursue the LEIF Physician Training was because they considered proper end-of-life care to be important (90.7%). Additionally, 63.6% of LEIF consultants in 2019 followed the LEIF physician training because they wanted to be able to support colleagues in medical end-of-life decision-making, 50.7% because they wanted to be prepared for an assisted dying request, and 42.9% because they were often confronted with assisted dying request. The proportion of LEIF consultants who indicated they were members of a palliative care team decreased, although not statistically significantly (15.1% / 25.4%). The proportion of LEIF consultants who had cared for fewer than five incurably ill patients at the end of life in 12 months changed significantly (27.0% / 52.1%, p=.001).

Table 2. Characteristics and end-of-life care experiences of Life End Information Forum (LEIF) consultants in 2008 and 2019

	2008 (N = 71)	**2019** (N=140)	**P–value for change between 2008 and 2019†**
	%	**%**	
Sex, Male	67.6	55.7	.104
Age			**.006**
< 40 years	9.9	25.0	
40 – 59 years	70.4	40.7	
≥ 60 years	19.7	34.3	
Medical speciality			>.999
General practitioner	73.2	72.1	
Other medical specialist‡	26.8	27.9	
Number of years working as a LEIF consultant			*
< 5 years	*	43.6	
5 – 9 years	*	30.8	
10 – 14 years	*	17.1	
≥ 15 years	*	8.5	
Motivation to pursue LEIF Physician Training§			

I consider proper end-of-life care to be important	*	90.7	*
I want to be able to support colleagues in medical end-of-life decision-making	*	63.6	*
I want to be prepared for an assisted dying request	*	50.7	*
I am often confronted with assisted dying requests	*	42.9	*
To obtain accreditation	*	3.6	*
Other	*	12.1	*
Additional end-of-life/palliative care training§			
Training in palliative care for patients with incurable illness||	*	39.3	*
Postgraduate inter-university training in palliative care	40.8	22.9	*
Study days and seminars on:			
Bereavement counselling	18.3	14.3	*
Pain management	*	49.3	*
Advance care planning	*	42.9	*
Breaking bad news	*	21.4	*
Existential and spiritual care	*	16.4	*
Member of palliative care team	25.4	15.1	.091
Number of incurably ill patients at the end of life cared for in the past year			**.001**
< 5 patients	52.1	27.0	
5 - 19 patients	32.4	56.2	
≥ 20 patients	15.5	16.8	

Percentages may not always add up to 100% because of rounding.

Missing values: Number of years working as a LEIF consultant (2019): n=23, Member of palliative care team (2019): n=1, Number of incurably ill patients at the end of life cared for in the 12 months prior to the questionnaire (2019): n=3

†P-value calculated with Fisher exact test (2 x 2 table) or Fisher-Freeman-Halton exact test (2 x 3 table) for changes in LEIF consultants' characteristics and end-of-life care experiences between 2008 and 2019. An alpha level of $p < .05$ defined statistical significance.

‡Other medical specialisms included psychiatry, anaesthesiology, oncology/radiotherapy, neurology and geriatrics.

*Question was not included in the 2008 questionnaire or asked in a different manner. As such, p-value could not be calculated.

§Percentages do not add up to 100% because multiple answers were possible.

||Five-day training organized by the Life End Information Forum on palliative care and care for people with chronic and terminal illness (PALM training). The training focuses on pain and symptom management, psychological counselling, social care and existential suffering.

The characteristics and outcomes of LEIF consultants' activities regarding assessing assisted dying requests over 12 months

The number of patients for whom the LEIF consultants were asked to assess an assisted dying request over 12 months did not change significantly between 2008 and 2019 (Table 3). In both years, about half the LEIF consultants (57.3% in 2008 and 50.0% in 2019) were asked for consultation on 1-4 patients over a 12-month period. The proportion doing so for 5 or more patients was slightly higher in 2019 (47.9% / 42.7 9.9%). In 2008, 95.8% and in 2019, 95.7% of LEIF consultants had carried out at least one consultation regarding an assisted dying request. Over 12 months, LEIF consultants in 2008 reported one to four patients who did not meet the criteria for assisted dying significantly more often than in 2019 (58.8% / 41.1%, p=.02). No statistically significant change was found in the proportions of LEIF consultants who were present at least once during the act (47.1% in 2008 and 61.9% in 2019), who helped at least once with the preparation of the act (44.1% in 2008 and 45.7% in 2019), or who administered the drugs for assisted dying at least once (36.8% in 2008 and 37.8% in 2019).

Table 3. Life End Information Forum (LEIF) consultants' activities as peer consultant for assessing assisted dying requests over 12 months in 2008 and 2019

	2008 (N=71) %	**2019** (N=140) %	**P–value for change between 2008 and 2019¶**
The number of patients for whom the consultant was asked to assess an assisted dying request			.467
0 patients	0.0	2.1	
1 - 4 patients	57.3	50.0	
≥ 5 patients	42.7	47.9	
Carried out at least one assessment of an assisted dying request as LEIF consultant	95.8	95.7	>.999
	2008 (N=68)‡ %	**2019** (N=132)‡ %	**P–value for change between 2008 and 2019¶**
Number of patients for whom the substantive requirements for assisted dying were not met			**.02**
0 patients	32.4	52.7	
1 - 4 patients	58.8	41.1	
≥ 5 patients	1.5	0.8	
Present with at least for one patient at the time of the act of assisted dying	47.1	61.9	.065
Helped at least for one patient with the preparation of the act of assisted dying	44.1	45.7	.878
Administered the drugs for assisted dying for at least one patient	36.8	37.8	>.999

Percentages may not always add up to 100% because of rounding.

Missing values: Had at least one consultation as a mandatory physician for an assisted dying request (2020): n=2, Number of patients for whom the substantive requirements for assisted dying were not met (2019): n=3, Present at least once at the time of the act (2019): n=14, Helped at least once with the preparation of the act (2019): n=16, Administered the drugs for assisted dying at least once (2019): n=13

¶ P-value calculated with Fisher exact test (2 x 2 table) or Fisher-Freeman-Halton exact test for changes in LEIF consultants' activities between 2008 and 2019. An alpha level of p < .05 defined statistical significance.

‡ For analyses regarding 'Number of patients for whom the substantive requirements for assisted dying were not met', 'Present with least one patient at the time of the act of assisted dying', 'Helped at least for one patient with the preparation of the act of assisted dying', and 'Administered the drugs for assisted dying for at least one patient', we only included those LEIF consultants who had carried out at least one consultation as the mandatory physician for an assisted dying request.

The characteristics and outcomes of LEIF consultants’ most recent assessment of an assisted dying request

No statistically significant change was found in the medical speciality of the attending physician requesting consultation (Table 4). Attending physicians remained primarily general practitioners (80.9% in 2008 and 85.0% in 2019). We found a significant change in the attitude of the attending physician towards the assisted dying request. In 63.3% of cases in 2008, compared to 42.7% in 2019, physicians had already decided they wanted to grant the request (p=.002). In 29.4% of cases in 2008 compared to 54.6% in 2019, physicians had not made a final decision on whether to grant the request (p=.002). Further associative analysis showed that the change in attending physicians’ attitude towards the assisted dying request between 2008 and 2019 remained significant in the following groups: male patients, patients aged younger than 60 years, and patients diagnosed with cancer (not shown in Table).

In 2019, the patients for whom the assisted dying request was assessed were significantly more often aged 80 or older than in 2008, increasing from 9.1% to 30.5% (p<.001). Patients had cancer as a main diagnosis significantly less often (70.1% / 53.0%, p=.034). Suffering without prospect of improvement was most often mentioned as the reason for the patient to request assisted dying (79.4% in 2008 and 80.3% in 2019) and was also most frequently indicated as the most important reason (42.6% in 2008 and 48.9% in 2019). While loss of independence in daily life was significantly more often reported as the reason (from 29.4% in 2008 to 53.8% in 2019, p=.002), fear of suffocation was indicated significantly less often (from 16.2% in 2008 to 4.5% in 2019, p=.008). Further associative analyses showed that the change in loss of independence between 2008 and 2019 remained significant in the following groups: male and female patients, and patients less than 60 years old (not shown in Table). Additionally, further associative analysis showed that the change in fear of suffocation between 2008 and 2019 remained significant in the following groups: male patients, patients aged 60-79 and patients diagnosed with cancer (not shown in Table).

The outcome of the LEIF consultations did not change significantly between 2008 and 2019. The LEIF consultant judged that the due care requirements for assisted dying were met in 89.7% of consultations in 2008 and 85.6% in 2019. The reasons indicated most often for the due care requirements not being met was that other treatment options had not been sufficiently explored (4.4% in 2008 and 5.3% in 2019). Assisted dying was carried out in 69.1% of consultations in 2008 and 64.1% in 2019.

Table 4. Characteristics of Life End Information Forum (LEIF) consultants' most recent assessment of an assisted dying request in 2008 and 2019

	2008 (N = 68)	**2019** (N=132)	**P–value for change between 2008 and 2019***
	%	%	
ATTENDING PHYSICIAN CHARACTERISTICS			
Medical specialty			.543
General practitioner	80.9	85.0	
Other medical specialist	19.1	15.0	
Attitude towards the assisted dying request			
Had not made a final decision on whether or not to grant the request	29.4	54.4	**.002**
Had decided to grant the request	63.3	42.7	
Had decided not to grant the request	7.4	2.7	
PATIENT CHARACTERISTICS			
Sex, Male	53.7	43.0	.175
Age			**<.001**
< 60 years	31.8	13.7	
60 -79 years	59.1	55.7	
≥ 80 years	9.1	30.5	
Main diagnosis			**.034‡**
Cancer	70.1	53.0	
General deterioration	7.5	15.2	
Neurological disorder	3.0	12.1	
Heart failure	0	3.8	
Psychiatric disorder	4.5	3.8	
COPD	1.5	2.3	
Other diagnosis	13.4	9.8	
Reason(s) for requesting assisted dying§			
Suffering without prospect of improvement	79.4	80.3	>.999
Loss of independence in daily living	29.4	53.8	**.002**
Loss of dignity	48.5	51.5	.766
General weakness or tiredness	44.1	47.7	.656
Pain	33.8	40.9	.360
Disability	20.6	26.5	.390
Not wanting to be a burden on the family/environment	16.2	22.7	.356
Tired of living	23.5	22.0	.859
Anxiety	7.4	9.1	.793
Depression	2.9	5.3	.507
Fear of suffocation	16.2	4.5	**.008**
Vomiting	2.9	3.8	>.999

Other reason(s) | |	5.9	9.1	.585
Most important reason for requesting assisted dying			.597†
Suffering without prospect of improvement	42.6	48.9	
Loss of dignity	14.7	13.0	
Pain	7.4	11.5	
Loss of independence in daily living	7.4	6.9	
General weakness or tiredness	10.3	5.3	
Fear of suffocation	5.9	2.3	
Tired of living	4.4	3.8	
Disability	1.5	3.1	
Anxiety	1.5	3.1	
Depression	1.5	0.8	
Other reason	2.9	1.5	
OUTCOME OF LEIF CONSULTATION			
Substantive requirements were judged to be met	89.7	85.6	.509
Substantive requirements were judged not to be met because other treatment options had not been sufficiently tried out	4.4	5.3	>.999
Substantive requirements were judged not to be met because there was no unbearable suffering	2.9	2.3	>.999
Substantive requirements were judged not to be met because there was no medically hopeless situation	1.5	2.3	>.999
Substantive requirements were judged not to be met because the request was not voluntary	0.0	0.8	>.999
Substantive requirements were judged not to be met because the request was not well-considered	0.0	1.5	.549
Substantive requirements were judged not to be met because the patient was not legally competent	0.0	1.5	.549
Substantive requirements were judged not to be met because of other reason(s)	2.9	2.3	>.999
Assisted dying was carried out			.430¶
Yes	69.1	64.1	
No	14.7	19.8	
Assisted dying procedure is still ongoing	5.9	**	
Unknown	10.3	16.0	

Percentages may not always add up to 100 because of rounding.

Missing values: Specialty of the attending physician (2019): n=5; Sex of the patient (2008): n=1, (2019): n=4; Age of the patient (2008): n=2, (2019): n=1; Main diagnosis of the patient (2008): n=1; Attitude of the attending physician towards the request for assisted dying (2019): n=22; Most important reason for requesting assisted dying (2019): n=1; Assisted dying has been carried out (2019): n=1

*P-value calculated with Pearson chi-square test for differences in characteristics and outcomes of the most recent LEIF consultation for an assisted dying request between 2008 and 2019. An alpha level of p < .05 defined statistical significance.

‡ We calculated the p-value for 'Cancer' or 'Non-cancer' with a Fisher exact test since the Pearson chi-square could not be calculated for all categories because more than 80% of the cell frequencies were less than 5.

† P-value calculated with Pearson chi-square test for 'Suffering without prospect of improvement', 'Loss of dignity', 'General weakness or tiredness', 'Pain', and 'Dependency'. Other categories were excluded because their cell frequencies were less than 5.

¶ P-value for yes / no. When omitting 'Assisted dying procedure is still ongoing' and 'Unknown' from the frequency analysis, 'Yes' represents 82.5% in 2008 and 76.4% in 2019, while 'No' represents 17.5% in 2008 and 23.6% in 2019.

§ Multiple answers were possible.

||Examples of other reasons include extreme dyspnoea, unable to live without partner, unbearable tenesmus, atrophy, chronic pain, social isolation.

**Answer option was not included in the 2019 questionnaire.

Adherence to quality criteria for consultation in LEIF consultants' most recent assessment of an assisted dying request

Adherence to the substantive requirement of independence from the attending physician and the patient did not change significantly between 2008 and 2019 (Table 5). The LEIF consultant was not a direct colleague (i.e., same working environment) of the attending physician in 95.0% of consultations in 2008 and 85.6% in 2019 and was not a co-attending physician in 100% of consultations in 2008 and 96.9% in 2019. The LEIF consultant did not know the patient in 92.5% of consultations in 2008 and 93.9% in 2019.

LEIF consultants discussed unbearable suffering (from 65% to 87%, p=.003), alternative palliative care treatments (from 13% to 48%, p<.001), and alternative curative treatments (from 5% to 28%, p=.002) with the attending physician significantly more often. The proportion of LEIF consultants who studied the patient's medical records increased significantly from 75.0% in 2008 to 87.9% in 2019 (p=.027). Further associative analysis showed that the change in studying medical records between 2008 and 2019 remained significant in the following groups: male LEIF physicians, LEIF physicians aged 40-59 years, LEIF physicians being general practitioners, and LEIF physicians taking care of 5-19 incurably ill patients at the end of life during the past year (not shown in Table). No significant change was found in the proportion of LEIF consultants who talked to and/or examined the patient (92.6% in 2008 and 94;7% in 2019) and made a written report about the consultation (58.8% in 2008 and 62.9% in 2019).

Table 5. Adherence to quality criteria for consultation* in LEIF consultants' most recent consultation for an assisted dying request assessment in 2008 and 2019

	2008 (N =68)	**2019** (N= 132)	**P-value for change between 2008 and 2019†**
	%	**%**	
The LEIF consultant			
1. was not a colleague of the attending physician**	95.0	85.6	.250
2. was not a co-attending physician‡§**	100	96.9	.574
3. did not know the patient‡**	92.5	93.9	.720
4. discussed the request with the attending physician on the telephone or face-to-face	100	93.9	.053
5. discussed the following topics with attending physician‡			
a) the hopelessness of the medical situation**	90.0	92.4	.741
b) the unbearable suffering of the patient**	**65.0**	**87.1**	**.003**
c) the well-considered nature of the request	77.5	78.0	>.999
d) the sustainability of the request	60.0	75.8	.069
e) the voluntary nature of the request	60.0	70.5	.247
f) possible alternative palliative treatment(s)	**12.5**	**47.7**	**<.001**
g) whether it is justified to perform euthanasia in this situation	27.5	39.4	.194
h) the method of performing euthanasia	47.5	37.9	.357
i) possible alternative curative treatment(s)	**5.0**	**28.0**	**.002**
6. talked to/examined the patient**	92.6	94.7	.546
7. talked to the patient's family	76.5	75.0	.863
8. studied the patient's medical records**	**75.0**	**87.9**	**.027**
9. made a written report on the consultation**	58.8	62.9	.646

Missing values: Is not a co-attending physician (2019): n=1; did not know the patient (2019): n=1

*Consultation quality criteria are derived from legal requirements (**) and criteria that have been proposed by previous research and taught during the LEIF Physician Training. [4,8,10,11]

**Procedural requirements under the assisted dying legislation in Belgium.

†P-value calculated with Fisher's exact test for differences between 2008 and 2019 in adherence to quality criteria for consultation in LEIF consultants' most recent consultation prior to the questionnaire. An alpha level of $p < .05$ defined statistical significance.

‡Data were obtained from the attending physician in the 2008 survey (n=40), instead of the LEIF consultants.[19]

§This refers to involvement in the patient's care prior to the assisted dying request.

Discussion

Main findings of the study

Using data obtained from LEIF consultants, we studied changes in the peer consultation practice of LEIF consultants between 2008 and 2019. In both years, seven in ten LEIF consultants were GPs, and two in five were engaged in at least one assessment of assisted dying in the year prior to the study. In 2019, assessments of assisted dying requests were more often for patients aged 80 years or older. In both years, cancer was most often the main diagnosis and suffering without prospect of improvement was the most reported reason for requesting assisted dying. Regarding adherence to quality criteria for consultation, in 2019, LEIF consultants discussed the patient's unbearable suffering and alternative treatments with the attending physicians more often and studied the patient's medical records more often.

Strengths and limitations of the study

A strength of this study is that it investigates changes over time in the assessment of assisted dying requests from the perspective of trained consultants. This perspective is not often addressed, as other studies mainly approach the practice using the perspectives of attending physicians, for example by means of mortality follow-back studies and studies of reported cases. Another strength of our study is that we examined the characteristics and quality of the peer consultation practice in the context of assisted dying and identified changes over time herein. Studies on this topic are scarce as research especially focus on describing the characteristics of assisted dying requests that were carried out. Our study is particularly relevant for other jurisdictions in which peer consultation prior to assisted dying is a legal requirement, such as Canada, some Australian states, the Netherlands, some US states, Luxembourg, and Spain.[1] For these jurisdictions, our findings might provide insights into frequently occurring topics and issues in peer consultations. As such, jurisdictions may have a better understanding of which aspects of the consultation practice and consultant training should be adjusted and refined in order to maximize its inherent quality. Moreover, our findings could be used to predict how the peer consultation practice might change over time in other jurisdictions. In this way, jurisdictions can better anticipate 'foreseen' changes in the peer consultation practice, and thereby assisted dying practice. Our study reported fairly high response rates, which is rather exceptional for surveys with physicians. However, this study also has limitations. There may be some recall bias, as questions were asked about consultants' most recent assessment of an assisted dying request up to 12 months prior to the questionnaire. However, performing assisted dying can be considered a profound event in the medical practice of physicians, thereby limiting the occurrence of recall bias.[20] Some of the data on quality criteria for consultation were gathered in different ways across study years. There might be some selection bias due to non-response, as not all LEIF consultants participated in the studies, although we sought to reduce this by conducting non-response surveys. For some variables, changes between 2008 and 2019 could not be identified, potentially due to the low absolute number of LEIF consultants included in the analysis.

Meaning of the findings and comparison with other studies

Over 11 years, we have observed several notable changes in the profile and number of LEIF consultants, the number of assessments of assisted dying requests, and the patients for whom assessment is requested. The increase in the number of LEIF consultants suggests that the 'early adopters' in 2008, who more often had a background in palliative care, have since been joined by a broader group of physicians who are frequently confronted with end-of-life matters, i.e. 'late adopters'. However, the increase in LEIF consultants has not kept up with the increase in requests for assessing assisted dying requests, as the proportion of LEIF consultants with 5 or more assessments over 12 months increased notably. Additionally, a shift has occurred in the profile of patients whose assisted dying request is assessed. In 2019, patients were more often aged 80 years or older, had age-related pathologies and multimorbidity more often, and were diagnosed with cancer less often. These shifts reflect a general shift in assisted dying practice found in other surveys and official reports [14,17,21] and also point to increased involvement of LEIF consultants in complex assisted dying requests, e.g. cases of multimorbidity that may require specific expertise. As substantive requirements can be difficult to assess in complex assisted dying requests,[22] it is paramount that LEIF consultants have adequate expertise in age-related pathologies and sensitivity to the context of older people's lives. As such, training in assessing assisted dying requests should be adapted to account for the changing patient population requesting assisted dying. Interestingly, we also found an increase in the number of patients younger than 60 years requesting assisted dying in 2019, partially because of fear of loss independence in daily life. This suggests a change in moral identities, with patients in this age group emphasizing their autonomy and independence more strongly than in 2008. In literature, however, loss of independence as the reason for requesting assisted dying has been attributed mainly to elderly patients.[23] This sheds new light on how care and guidance surrounding assisted dying for these patients should ideally be organized. It seems pivotal to focus on the needs of these patients in relation to their autonomy and independence.

Our findings indicate some improvements in adherence to quality criteria for consultation, such as discussing patients' unbearable suffering and alternative treatments, and consulting patients' medical files. These improvements may indicate increased awareness of quality criteria among LEIF consultants, possibly due to a greater emphasis on it in the LEIF training in recent years. For example, the current training pays more attention to frequently occurring difficulties in patient contact in assisted dying, and to present challenges and complexities in practice, such as assessing dying requests from elderly persons with age-related morbidities, or from adults with psychiatric conditions. However, we have found few shifts in LEIF consultants' independence or active involvement in the performance of assisted dying. This involvement goes beyond the official remit of LEIF consultants, and is explicitly contra-indicated in LEIF guidelines.[24] It is possible that attending physicians prefer a LEIF consultant to be present to provide support and/or guidance in the technical performance of assisted dying, as found in previous studies.[25–28] This indicates that attending physicians may feel insecure about performing assisted dying, which can be a complex and emotionally difficult task. Attention to adequate support for attending physicians in performing assisted dying may therefore be necessary in consultant training.

Interestingly, we found that procedural requirements were not always met in LEIF consultants' assessments of assisted dying requests in 2019. Physicians' non-compliance with procedural requirements of assisted dying has been described repeatedly in previous research.[8,11,29,30] Another reason might be that fulfilling certain procedural requirements is perceived as relatively unimportant or burdensome.[29] It is also possible that LEIF consultants decide not to carry out the whole range of procedural requirements because they have already judged that the request would not meet the substantive requirements based on initial assessment.

Implications for practice, policy and research

Our findings suggest that assisted dying practice benefits from a structural provision of peer support in the performance of assisted dying. In terms of practice implications, we recommend that the number of assessments of an assisted dying request should be in balance with consultants' individual work capacity. Such balance is pivotal in maintaining quality assurance of these assessments, as well as safeguarding consultants' wellbeing. A profusion of assessments might have a detrimental impact on both.[31,32] A certain minimum of assessments, on the other hand, is also warranted to ensure that consultants remain sufficiently experienced to fulfil specific practice needs in peer consultations. Hence, as the amount of assessments over 12 months per consultant seems to be rising, applying a more equal distribution of these assessments among all consultants is recommended to prevent consultants from performing too many assessments with a potentially negative effect. Furthermore, it seems appropriate for training in assessing assisted dying requests to be revised over time, taking into account the complexities and challenges of the evolving nature of assisted dying requests. Additionally, ongoing emphasis on adherence to procedural requirements and other quality criteria for consultation in training remains important, even after completing training. This can be established, for example, through mandatory follow-up trainings or communities of practice. Another recommendation to support or to maximize adherence to quality criteria and legal requirements might be developing and implementing a quality instrument in peer consultations, for example, a practice guide for consultants stipulating the different steps they have to follow to ensure high-quality consultations. As concerns recommendations for policy, it seems advisable to consider regular monitoring of the peer consultation practice of assessing assisted dying requests, as its quality may change over time, and to identify potential gaps in assisted dying practice. For example, regular monitoring may reveal whether practitioners still interpret and apply the legal requirements related to peer consultation as initially intended by the legislator. Future research could focus on studying changes over time in peer consultations on assessing assisted dying requests by practitioners who have not taken the specific formal training for assisted dying request assessors from health service organizations like LEIF. Moreover, insight into the impact of LEIF consultations on the quality of assisted dying practice is still lacking, e.g. in terms of performance of the act and support for involved health care professionals and patients' relatives.

Conclusion

We identified several changes in LEIF consultation practice between 2008 and 2019. These changes likely reflect changes in assisted dying practice in general and changes in the focus of LEIF consultations towards more complex cases for which LEIF consultants' expertise is required. Our findings highlight the importance of regular monitoring of the practice and tailoring the training of specialized consultants to trends over time to safeguard the quality of the practice.

Contributorship statement

SD, KC, LD and JC were responsible for the study's conception and design. SV and SD were responsible for data collection and analysis, and drafted the manuscript. All authors contributed to the interpretation of the data, critically revised the manuscript for important intellectual content, and gave final approval for submission. SV, SD and JC act as guarantors of the work. SV and SD contributed equally as first author.

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Chapter 4

The support needs experienced by patients requesting euthanasia and their relatives throughout the euthanasia trajectory: a qualitative study using semi-structured interviews and written narratives

Stijn Vissers, Joni Gilissen, Joachim Cohen, Luc Deliens, Freddy Mortier, Kenneth Chambaere*, Sigrid Dierickx*

*Joint final authors

Submitted

Abstract

Background: Euthanasia has become an increasingly prevalent practice at the end of life globally. Persons requesting euthanasia (patients) and their relatives might experience several difficulties and suboptimal outcomes throughout their euthanasia trajectories, i.e., from the moment when the patient has an explicit desire for euthanasia till the period following the performance of euthanasia. These difficulties and suboptimal outcomes may indicate that their support needs are not adequately addressed in practice or unknown by the healthcare professionals supporting them. However, we lack an in-depth understanding of their support needs experienced throughout their euthanasia trajectories. This study aimed to explore the support needs that patients and relatives experience throughout their euthanasia trajectories.

Methods: We carried out a qualitative study in Flanders and Brussels (Belgium) in 2022 using 1) semi-structured interviews with and personal written narratives (via qualitative questionnaire) of patients requesting euthanasia and 2) semi-structured interviews with relatives of patients requesting euthanasia. Data were collected using purposive and snowball sampling. We performed an interpretative thematic analysis.

Findings: We included the lived experiences of 15 persons requesting euthanasia and 21 relatives in our analysis. We identified eight themes or types of support needs that patients and relatives (participants) had experienced throughout their euthanasia trajectories. More specifically, participants needed support for 1) maximizing daily functioning (only reported by patients), 2) making sense of the unbearable suffering (only reported by relatives), 3) managing meaningful activities, 4) navigating existential questions, 5) psycho-emotional regulation, 6) facilitating social interaction, 7) understanding the process toward euthanasia, 8) and handling organizational and practical matters.

Conclusion: Our study reveals that patients and relatives might experience multidimensional support needs throughout their euthanasia trajectories. Moreover, our findings suggest that they rather experience their euthanasia trajectories as social-existential pathways than as medical ones. As their support needs essentially correspond with those experienced in other trajectories at the end of life, euthanasia support for patients and relatives might benefit from a palliative care approach to ensure and enhance its effectiveness in practice.

Introduction

Assisted dying, including euthanasia and physician-assisted suicide, has become an increasingly important legal and medical issue over the last decade. Euthanasia involves the practice in which a health practitioner, most often a physician, ends a person's life at their voluntary request by administering lethal drugs. Physician-assisted suicide involves the practice in which a health practitioner, most often a physician, provides or prescribes lethal medication to a patient on his or her voluntary request who subsequently self-administers it to end his or her life.[1] At present, jurisdictions with assisted dying legislation are home to about 300 million people across the globe.[1] Furthermore, prevalence rates of assisted dying continue to rise in jurisdictions where the practice is lawful, including several US states.[2–4]

Euthanasia entails a complex process as persons requesting euthanasia (hereafter referred to as 'patients') and their relatives may experience a range of challenges, difficulties, and undesired outcomes throughout their euthanasia trajectories.[5] These trajectories include the moment when the patient has an explicit desire for euthanasia, the assessment of the request, the performance of euthanasia, and the period following the performance of euthanasia.[5,6] Patients, for example, sometimes experience that their autonomy and values are not respected, and may feel that healthcare professionals (HCPs) and relatives minimize their unbearable suffering.[5,7,8] Relatives, for example, may feel unprepared for the performance of euthanasia, can experience post-traumatic stress after the performance, and may feel excluded by HCPs during the assessment of the euthanasia request.[9–14] These challenges, difficulties, and undesired outcomes may indicate that the support needs of patients and relatives are not adequately fulfilled, for instance, because their HCPs do not know their support needs or have not assessed them properly.[6,7,9,15]

Hitherto, the scientific literature provides little direction on the specific support needs of patients and relatives throughout their euthanasia trajectories. Studies have primarily focused on describing their general experiences with euthanasia practice, their attitudes towards euthanasia, problems and difficulties they encounter in euthanasia practice, and their interactions with HCPs who assess the request and carry out the performance.[8,16] A better understanding of the support needs of patients and relatives in euthanasia practice could guide HCPs in anticipating undesired outcomes and improving the quality of life of patients and relatives.[17] Furthermore, it may yield valuable insights for family caregivers on how to support better their loved ones requesting euthanasia.[15] We sought to answer the following research question: what support needs do patients requesting euthanasia and their relatives experience throughout their euthanasia trajectories?

Methods

Research paradigm and study design

We took on a social constructionist lens, assuming that support needs are social and dynamic constructs.[18] We recognized that patients and relatives actively construe and assign meaning to the support they require in their euthanasia trajectories through their lived experiences.[18] Due to the explorative nature of our research aim, we employed a qualitative design capturing the lived experiences of euthanasia practice among patients and relatives, using 1) semi-structured interviews with patients and relatives and 2) personal written narratives from patients through qualitative questionnaires.

We followed the Consolidated Criteria for Reporting Qualitative Research (COREQ) for reporting.[19]

Study context

We conducted this study from December 2021 to September 2022 in Flanders and Brussels (Belgium), home to 68 % of the Belgian population. For a patient to be eligible for euthanasia, specific criteria must be met, which are stipulated in the Belgian Act on Euthanasia.[20] In Belgium, euthanasia is mainly performed in the home setting (54% of all cases in 2020-2021), hospitals (30%), and nursing homes (13%).[21]

Research participants, recruitment, and data collection

We included patients and relatives having lived experiences with euthanasia practice. Eligibility criteria for patients were: 1) having expressed a desire for euthanasia to relatives (friends or family members) or HCPs, or having formally requested euthanasia to an attending physician, or having received the formal approval from an attending physician to receive euthanasia; 2) being comfortable with being interviewed in Dutch; 3) residence in Flanders or Brussels, Belgium; and 4) being 18 years or older. Eligibility criteria for relatives of patients were: 1) being a family member or friend of a person who has expressed a desire for euthanasia or has formally requested euthanasia, or who has received the formal approval to receive euthanasia, or who received euthanasia prior to the interview (between three months and three years), 2) fluency in Dutch; 3) residence in Flanders or Brussels, Belgium; and 4) being 18 years or older.

We recruited participants between December 2021 and June 2022 using purposive and snowball sampling. We aimed to recruit a heterogeneous study sample in terms of sociodemographic characteristics, health conditions, and principal care settings. More specifically, purposive sampling occurred through healthcare and patient organizations and associations, stakeholders, and the professional network of the End-of-Life Care Research Group in Flanders (Belgium). Snowball sampling was applied by inviting potential participants who were identified by included participants for study participation. Interested participants could register on a website or contact the research team. We conducted an eligibility assessment before inviting them to participate in the study. Eligible patients were allowed to participate via a semi-structured interview or a personal written narrative using an online qualitative questionnaire (LimeSurvey).

For the semi-structured interviews, we used a topic guide consisting of the following topics: 1) general experiences with euthanasia practice; 2) experienced malpractices regarding euthanasia; 3) experienced good practices regarding euthanasia, and 4) experienced support needs regarding euthanasia. Support needs were conceptualized as the support or guidance a participant experienced as essential to meet his or her basic needs or to achieve a desired outcome in euthanasia practice.[22] Participants could choose whether the interview would be performed online by Whereby (Whereby.com) or in person at a location of their choice. JG (second author) conducted one interview, while SV (first author) conducted the other interviews. Interviews were recorded and transcribed verbatim. After every interview, field notes were made to document unique observations and contextual information. For the personal written narratives, we sent an online qualitative questionnaire to eligible patients who preferred this method of study participation.[23] The questionnaire included open-ended questions reflecting the themes of the semi-structured topic guide. We requested patients to respond to these questions by writing down their narratives and experiences, which we converted into transcripts for data analysis.[23] Data collection was informed by inductive thematic saturation in which we defined the saturation point as five consecutive interviews or narratives without the emergence of new meaning related to the themes of support needs.[24]

Data analysis

We used a multi-phased interpretative thematic approach.[25,26] In the first phase, SV and SD applied open inductive coding and categorization of the raw data. We linked initial codes to text fragments, aiming at identifying initial codes describing participants' lived experiences of support needs regarding euthanasia. Support needs were conceptualized following the definition used during data collection.[22] SV and SD independently created a coding framework based on seven transcripts. These frameworks were then compared: inconsistencies and differences were discussed until a preliminary coding framework was reached. Next, SV used the coding framework to analyze the remaining transcripts, modifying it when new codes emerged. We used Nvivo 12 for the coding process. In the second phase, SV merged codes similar in understanding into themes to identify and define themes related to support needs. Based on the data from patients and relatives, we concluded that saturation was reached after the 26th interview as no new meaning in relation to their support needs had arisen.[24] In the third phase, the identified themes were discussed in group meetings with all co-authors. Again, inconsistencies were addressed until an agreement on final themes was reached. The field notes were used to help us organize the codes and identify themes.

Quality criteria

We used several strategies to enhance the quality of our qualitative study: 1) method triangulation, including semi-structured interviews, written narratives, and field notes; 2) investigator triangulation involving multiple researchers (all authors) with different backgrounds (sociology, ethics, and social work) for the study conceptualization, data collection, and data analysis; and 3) ongoing reflexivity of the research team through bimonthly group meetings with all authors.[27]

Ethical considerations

The Ethics Committee of the Brussels University Hospital and Vrije Universiteit Brussel approved our study (BUN 143202100057; 15 September 2021). We utilized pseudonyms for all participants in the transcripts and removed any identifying information. All participants provided written or oral informed consent to participate in the study. Due to the sensitivity of our research topic and potential impact, we offered free access to psychological counseling for participants. However, none of the participants requested this. Furthermore, we allowed participants to have someone familiar present during the interview as emotional support. One patient made use of this option. Consequently, we conducted a dyadic interview as this familiar person was a relative eligible for study participation.

Results

Study sample

We identified 18 patients and 23 relatives as eligible for study participation, of whom 15 patients and 21 relatives (n=36) eventually participated. Tables 1 and 2 report their main characteristics. We conducted 9 semi-structured interviews with patients (5 online interviews), 5 written narratives from patients, 1 dyadic semi-structured interview with a patient and a relative (in person), and 20 semi-structured interviews with relatives (11 online interviews). Three patients and two relatives dropped out of the study without a statement of specific reasons. The mean length of the semi-structured interviews with patients was 78 minutes (range: 28 – 130 minutes), and 82 minutes (range: 54 - 127 minutes) with relatives.

Table 1. Participant characteristics of patients requesting euthanasia (N=15)

	N
Sex	
Female	12
Male	3
Age	
< 30 years	1
30 – 40 years	4
41 – 50 years	4
51 – 60 years	3
> 60 years	3
Highest level of education	
Secondary school	6
Higher education	9
Phase in the euthanasia trajectory*	
Holding an explicit desire for euthanasia that has been expressed to relatives or HCPs	4
Exploration of the eligibility for euthanasia by the attending physician following a formal request	5
Preparing the performance of euthanasia as the attending physician has agreed to grant the request	6
Main medical diagnosis	
Psychiatric disorder	7
Connective tissue disorder	2
Chronic pain syndrome	2
Neurodegenerative disorder	2
Cancer	2

Main residency*	
Home	13
Hospital	1
Nursing home	1
*Timing of the interview or written narrative	

Table 2. Characteristics of relatives (N=21)

	N
Sex	
Female	18
Male	3
Age	
< 30 years	1
30 – 40 years	6
41 – 50 years	2
51 – 60 years	6
> 60 years	6
Highest level of education	
Secondary school	2
Higher education	19
Relationship with the patient	
Partner	2
Parent	3
Sibling	1
Child	9
Grandchild	2
Close friend	1
Living together with the patient*	
No	18
Yes	3
Family caregiver*	
Yes	11
No	9
The phase of euthanasia practice*	
The patient holds an explicit desire for euthanasia, that has been expressed to relatives or HCPs	0

Exploration of the eligibility for euthanasia by the attending physician following a formal request	2
Preparing the performance of euthanasia as the attending physician has agreed to grant the request	3
Euthanasia was carried out**:	
< 12 months	7
12 - 24 months	5
25 - 36 months	3
> 36 months	1
Patient's main medical diagnosis*	
Cancer	12
Neurodegenerative disorder	3
Psychiatric disorder	2
Chronic pain syndrome	2
Polypathology	2
Patient's sex	
Female	13
Male	8
Patient's age*	
< 30 years	1
30 – 40 years	2
41 – 50 years	1
51 – 60 years	2
61 – 70 years	4
71 – 80 years	7
> 80 years	4
Patient's main residency*	
Home	14
Hospital	4
Nursing home	3

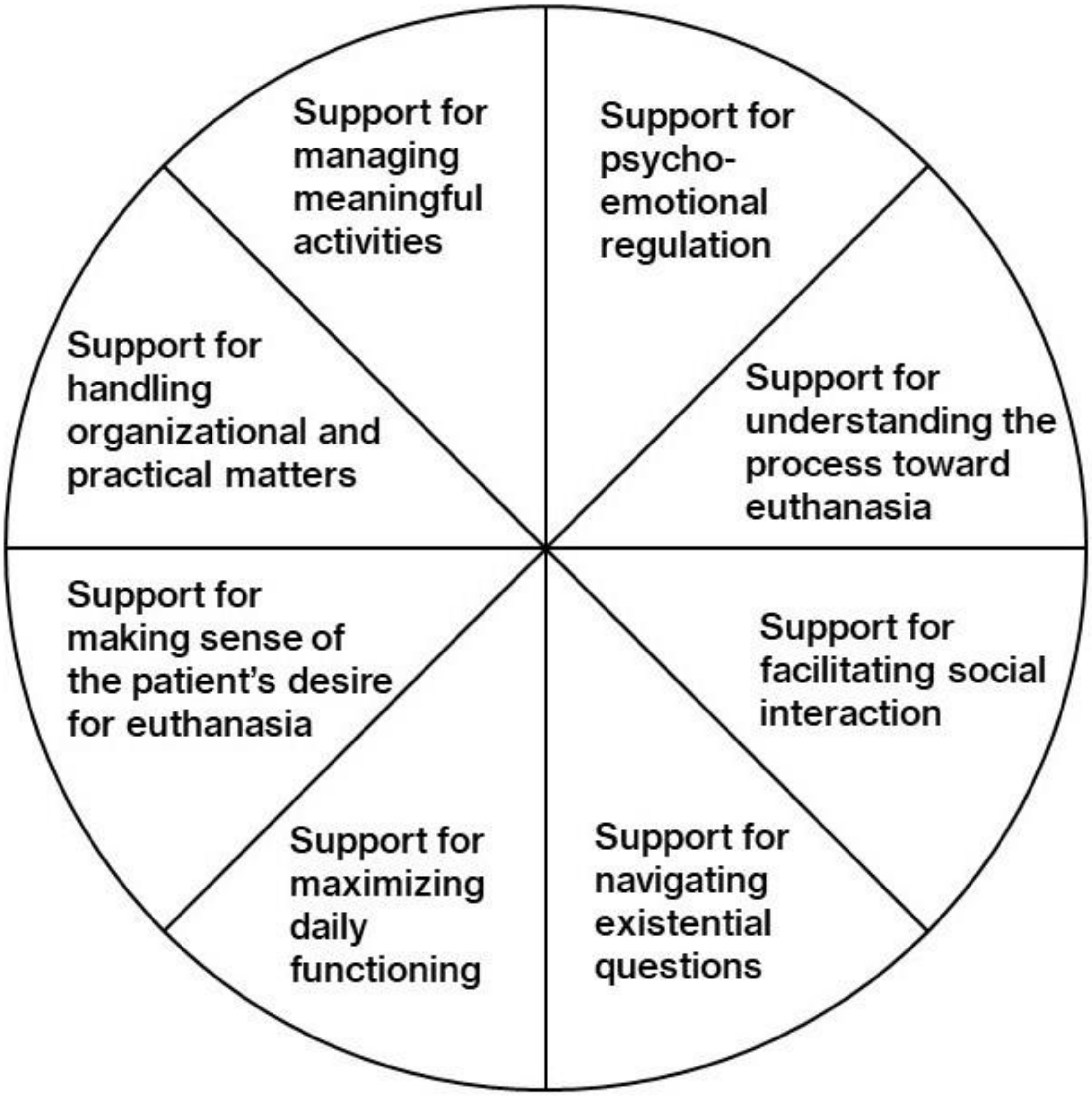
*Timing of the interview or when the euthanasia was carried out.

** In one case, the relative did not attend the performance of euthanasia.

Support needs experienced throughout the euthanasia trajectory

We identified eight themes or types of support needs experienced by patients and relatives throughout their euthanasia trajectories (Figure 1). Identified support needs appeared to differ in their intensity of experience and seemed to be partially linked to a specific phase of the euthanasia trajectory: 1) the phase prior to the performance, including the periods when the patient holds an explicit desire for euthanasia, the patient formally requests euthanasia, the attending physician assess the patient's eligibility for euthanasia, and the performance of euthanasia is being prepared; 2) the phase (day) of performance; and 3) the phase following the performance. We discuss each theme or type of support need separately for analytic clarity. However, they are interconnected in practice. In the following paragraphs, references to 'participants' include both patients and relatives.

Figure 1. We identified eight types of support needs that patients and relatives had experienced throughout their euthanasia trajectories. Support for maximizing daily functioning was only found among patients, while support for making sense of the patient's desire for euthanasia only among relatives



Support for maximizing daily functioning

This support need was only found in patients. Patients repeatedly spoke of their unbearable suffering as a daily reality around which they had organized their lives. They described in many ways their ongoing struggle with accepting this suffering. Although patients recognized that no practical support could eradicate their suffering, some felt that support could ease their struggle by maximizing their daily functioning throughout their euthanasia trajectories. They favored practical support in carrying out daily activities and tasks, e.g., aid to travel to health care facilities. Some patients experienced such support as essential to maintaining a sense of self-worth. On the other hand, others experienced such support as pivotal to be able to stay at home independently and to receive euthanasia in their familiar environment.

"Well, you won't recover if you have a chronic disease. So it's not about recovering. It's a different way of looking at me. I also know that, in my case, being at home is not the ideal situation because I don't have the same support as in the hospital. There, you got pain management, a nursing team helping you out of bed and giving you all the medication, and if they have to, even putting the food in your mouth. I don't need that kind of support. That is way too much, of course. But just a bit more support, so I am more comfortable at home. This would be helpful, so I can stand on my own feet and stay here at home with my dog until it's time for my euthanasia."

- Patient preparing the performance of euthanasia -

Support for making sense of the patient's desire for euthanasia

This support need was only identified in relatives. Relatives needed support for making sense of the patient's desire for euthanasia and its broader context, such as the nature of the unbearable suffering. Most relatives needed this to 1) facilitate closure and accept the patient's desire and 2) evaluate their potential role in alleviating the suffering. Relatives stated that this support need partially stemmed from their limited understanding of the desire for euthanasia as patients and HCPs often reduced the desire to the patient's medical condition.

"I think it would have been better if we were a bit more informed about her suffering, and especially about the severity of her suffering. Of course, that's very personal, but that would have helped us to evaluate her situation in a realistic way and perhaps to assist her better. A bit like raising awareness. Now, I can finally imagine what her suffering was all about, but before... Mum makes the decision for euthanasia and stops

all treatments. Two weeks later, she was dead, and we were still unsure of why she had chosen to go through with euthanasia."

-Relative of a patient who received euthanasia-

Support for managing meaningful activities

Patients and relatives (hereafter referred to as participants) felt the need to experience moments and activities that gave purpose and meaning to their euthanasia trajectories as ways to make the most of the remaining time prior to the performance. In practice, these meaningful moments and activities reflected participants' values, passions, lives, roles, and identities, particularly those of patients. These included, for example, preparing memorials, sharing (life) stories and memories, and participating in rituals and traditions. Participants particularly experienced a farewell ritual as one of the most meaningful activities. Moreover, relatives also identified being a family caregiver for the patient in his or her euthanasia trajectory as a meaningful activity. However, participants needed support to manage meaningful activities as they often faced difficulties and challenges. Additionally, patients with a non-terminal condition most often found their euthanasia trajectories to be long and purposeless and stipulated that they required support in finding meaningful activities prior to the performance.

"I would prefer to call it the need for a master of ceremonies. Perhaps that's a weird word, but someone who actually guides us in our farewell ritual. When I say farewell ritual, everyone thinks of the farewell ritual in the mortuary. So I don't need him for that, but for a farewell ritual on the day of the performance, together with my family. Someone who helps you in looking for alternative ways to say goodbye. Someone who normalizes the whole situation on the day itself, and in which my brother and mother are given a special part."

-Patient preparing the performance of euthanasia-

Support for navigating existential questions

Participants expressed having many existential questions and contemplating life and death throughout their euthanasia trajectories. This involved questioning and reflecting upon, for example, the value of life, when it is justified to request euthanasia, what will come after death, whether requesting euthanasia equals failing relatives, or when one is ready to die. Consequently, participants emphasized their support need for navigating existential questions as having a sounding board since these questions sometimes led to feelings of loneliness and distress. Furthermore, this support need appeared more acute in patients than in relatives.

"I also think the philosophy around it is important. What does this mean in a more existential context? I am not religious, but what does such a euthanasia request from your child mean? What is the impact of that? Have I been a good parent? Is it something genetic? What was my role in her decision to make the request? It's not just the practical side that matters, but also, how do I deal with this? What does it mean? Should I ask myself questions about how I stand in life? These questions are ever-present. Fortunately, I don't get completely overwhelmed by these questions, otherwise, I would spiral into depression. However, I still contemplate them regularly. I have numerous questions, observations, and reflections that are difficult to be answered. It's a state of mind that persists even when I am in bed at night. This can lead to mental turmoil, making it impossible to get any sleep. So yeah, then it would be nice to have someone to listen to them and acknowledge my concerns. That could provide some comfort, yes."

-Relative of a patient whose attending physician is assessing the eligibility for euthanasia-

Support for psycho-emotional regulation

A rapid succession of negative and positive emotions characterized participants' euthanasia trajectories. They particularly stressed the need for guidance in controlling and coping with negative emotions. Participants often felt overwhelmed by the intensity of their emotions and faced difficulties processing them independently. Patients' negative emotions included anxiety due to the uncertain outcome of the euthanasia request, distress caused by the unpredictable progression of the unbearable suffering, and fear of death and the unknown afterlife. Negative emotions of relatives included feelings of loss and (anticipatory) grief throughout their euthanasia trajectories, stress when the request is being assessed, and tension upon receiving the news of the patient's request.

The need for psycho-emotional regulation seemed to differ in intensity among participants. In their accounts, participants experiencing adverse events in their euthanasia trajectory emphasized their need for psycho-emotional regulation more strongly compared to those not experiencing adverse events. Additionally, family caregivers or relatives very close to the patient also stressed their need for psycho-emotional regulation more firmly in their accounts compared to others. These relatives attributed this need in part to the fact that they neglected their emotions due to prioritizing the patient's emotions as the focal point throughout the euthanasia trajectories.

“That moment itself [after performance], you are in the flow of the funeral and family. But the night after, it was, it was really awful. Yes, you are in shock. When someone you love dies due to a sudden accident or illness, you are in shock because you have not been able to prepare for it. We had a year to prepare ourselves for her death as we had arranged her euthanasia well in advance. But I was in shock. […] A month later, I ended up with a psychologist through my general practitioner. I didn't know what to do with what I felt or didn't feel. Is it normal for me to think such things? And then someone who says to you ‘That's completely normal’ is just enough."

-Relative of a patient who received euthanasia-

Support for facilitating social interaction

Participants felt a strong need for social connection and sharing their euthanasia trajectories with their loved ones, who were often indicated as the most important individuals in their trajectories. However, many participants reported problems establishing and maintaining social interactions and wished for support to facilitate this.

The support need for facilitating social interaction was materialized by participants in several ways. First, some participants required support to resolve social conflicts and to improve social bounds, e.g., conflict resolution through moderated family conversations. This support need was partly related to obtaining peace of mind before the performance. Moreover, some patients considered postponing the performance if social conflicts were not resolved. Second, a few patients needed social support in communicating their euthanasia wishes or requests to relatives. Third, some relatives perceived this support as facilitating family engagement in the euthanasia trajectories. These relatives experienced family engagement as necessary to adequately support patients in their euthanasia trajectories. Relatives who were at times not being engaged, experienced frustration or anger, sometimes resulting in psychological problems.

“It would be useful to have someone as a backup, indeed. I have always had a good relationship with my brothers, you know. One of them is Catholic, and the others are atheistic. Anyway, when we are together, that can cause some problems, and even more now when I have asked for euthanasia. Sometimes, you can really feel the tension. But you can’t always be diplomatic if that is what I want. But it would help if there is a moderator. We often meet as brothers, but we don’t really talk to each other about our feelings. That’s difficult. So yes, a moderator to help us say what we still want to say to each other before I get euthanasia.”

–Patient whose attending physician is assessing the eligibility for euthanasia-

Support for understanding the process toward euthanasia

In their euthanasia trajectories, participants required support for understanding the process toward euthanasia regarding 1) the euthanasia legislation and procedure, and 2) the attending physician's decision-making regarding euthanasia. First, participants found it challenging to comprehend the legal modalities of euthanasia, especially the eligibility criteria. These difficulties led to confusion and ambiguity, such as whether patients with advanced dementia have access to euthanasia via an advance directive. In addition, participants wanted guidance in understanding the euthanasia procedure, including the formal steps one must complete before the performance. Second, participants required guidance in understanding the attending physician's decision-making process for granting or rejecting the euthanasia request. Participants wanted to know the specific motives or reasoning behind the decision, partly due to their experiences with vagueness from attending physicians.

"Perhaps the oncologist could have framed it better: from the moment you decide that you want euthanasia, this and that still have to happen first. We didn't know that. Mom called the hospital to say she would like to receive euthanasia. All the necessary paperwork was in order. However, at that point, she was told that a second doctor was needed. We also didn't know that you couldn't come into the hospital and have it done right away."

-Relative of a patient who received euthanasia-

Support for handling organizational and practical matters

Participants required assistance with various organizational and practical matters throughout their euthanasia trajectories, such as deciding on the ideal location and timing of performance or arranging the patient's funeral. They also needed help with administrative tasks, e.g., completing a written euthanasia request to meet the legal requirement.

Participants explained that this support need partly stemmed from their desire to focus on issues that mattered more to them than organization and practical matters, such as social activities. Organizational and practical support was perceived as a way to reduce the administrative burden often experienced in euthanasia practice. On the other hand, some patients wished for this support to be in order with all administrative requirements as a sense of control or relief. That was more acute in relatives than patients because handling organizational and practical matters was perceived as one of their important roles since patients often lacked strength due to their general deterioration.

"One thing that was lacking in terms of support during my hospital stay was the absence of social service to help me with the arrangements necessary for the performance of euthanasia. I had to carry out everything on my own, without any prior experience of making a written request, knowing whom to notify, or what to take into account. That was a time-consuming and energy-draining process, and it would have been helpful if there was a social service to rely on. Someone who could be present when arranging these things; and also help me locate a notary in the area. The practical details that needed to be taken care of were a burden, and while those around me have tried to help me, I don't think it should have been their responsibility to shoulder this."

-Patient preparing the performance of euthanasia-

Discussion

Using semi-structured interviews and written narratives, we identified various support needs among patients and relatives across their euthanasia trajectories -i.e., from the moment when the patient has an explicit desire for euthanasia till the period following the performance of euthanasia-. Participants needed support for maximizing daily functioning (only reported by patients), making sense of the patient's desire for euthanasia (only reported by relatives), managing meaningful activities, navigating existential questions, psycho-emotional regulation, facilitating social interaction, understanding the process toward euthanasia, and handling organizational and practical matters.

Our study suggests that euthanasia constitutes a multidimensional practice for patients and relatives involving various support needs throughout their euthanasia trajectories. These support needs essentially reflect a much patients' and families' broader aspiration, definition, and experience of the conditions for a good death.[28–31] Although echoing some degree of specificity in terms of context and practice – e.g., making sense of the patient's desire for euthanasia and understanding the process toward euthanasia- most identified support needs seem to correspond to the multidimensional support needs of patients and relatives in other end-of-life trajectories.[32–34] Our findings could be seen to align with Manfred Max-Neef's theory which states that (support) needs across individuals and practices are highly similar, as opposed to traditional theories asserting considerable variation in (support) needs.[35] Hence, an interprofessional approach can be warranted to meet the multidimensional support needs throughout the euthanasia trajectory as it can be challenging for a single professional to address all of these needs alone.

Our study illustrates that, in line with other dying experiences, patients and relatives experience their euthanasia trajectory less as a medical practice and more as a social and personal process.[36] This is substantiated by our finding that participants needed support for facilitating social interaction while emphasizing their intense need for social connection and sharing their final moments throughout their euthanasia trajectories. The social character of euthanasia practice is also evident in relatives' need for support to be engaged in the euthanasia trajectories, making them active participants. These results build on previous studies indicating that euthanasia should be equally understood and approached as a social and relational phenomenon.[8,12,37] This implies that the euthanasia trajectories of patients and relatives are partly nurtured by the dynamics and quality of their relationships, which may influence their euthanasia experiences considerably.[12,37] In that way, our findings provide empirical evidence for suggestions of Canadian scholars that assisted dying support would benefit from both a patient- and family-centered approach.[7,13,38] Furthermore, 'euthanasia as an existential practice' is substantiated by the fact that participants needed support for navigating existential questions, managing meaningful activities, and making sense of the unbearable suffering in the case of relatives. This is in keeping with the study of Tuva et al., which found that patients near the end of life longed for care focusing on 'living a meaningful life'.[32] Furthermore, these support needs may result from the typical existential experiences that are often reported among patients and relatives when death is imminent.[39,40] Moreover, our participants experienced farewell rituals in their euthanasia trajectories as particularly meaningful. That corroborates previous research, in which relatives perceived these farewell rituals as an advantage of euthanasia practice as they experienced that in other end-of-life practices, they had less room to organize them due to the unpredictable nature of the moment of death.[12,41] Successful farewell rituals may provide individuals with emotional energy and facilitate closure.[41,42] Furthermore, our study suggests that patients and their relatives struggle to organize and manage meaningful and meaning-making activities. A plausible reason is that such tasks might come with an emotional burden and some unfamiliarity.[5]

Our study further raises the interesting question about which support model would be best suited to meet the support needs of patients and relatives in euthanasia practice. In line with others,[7,43,44] we argue that a palliative care approach seems to be highly suitable, based on our findings' alignment with the principles and goals of palliative care: 1) patients requesting euthanasia and relatives require support for the multidimensional needs they experience with a strong emphasis on psychological, social and existential needs; 2) an interprofessional approach is advisable to fulfill the multitude of these support needs adequately; and 3) patient-and family centeredness appears the most appropriate approach. These requirements mean that palliative care professionals and services are well suited to address the support meets of patients and relatives in euthanasia practice. Thus, palliative care and euthanasia practice should not necessarily be viewed as opposing options but might be integrated, as in Belgium.[45] The integration of palliative care and euthanasia practice continues to be the subject of intense international debate.[46,47] Our study provides empirical support in favor of this integration. We suggest that jurisdictions with (proposed) assisted dying legislation should consider in earnest to what extent and how palliative care professionals can be engaged, and organizations can be strengthened, to support patients and relatives throughout their euthanasia trajectories.

Limitations and strengths

Several study limitations should be considered relating to potential bias in the findings. First, some psychological adjustments and recall bias regarding earlier experiences in the euthanasia trajectories may be possible (e.g., because of memory limitations and emotional influences), resulting in reporting predominantly positive or negative experiences. Second, we could have missed some specific support needs of patients with terminal conditions as we mainly recruited patients with non-terminal conditions. This was partly due to self-selection in participant recruitment, but we mitigated this by including numerous euthanasia experiences from relatives of patients with terminal conditions. On the other hand, various study strengths can be acknowledged. We used several strategies to enhance the rigor and trustworthiness of our findings: method triangulation, investigator triangulation, and ongoing reflection.[27] We also used a combination of semi-structured interviews and written narratives to capture the experiences of patients reluctant to participate through interviews, thus aiding inclusivity and reducing potential recruitment bias. We obtained a saturation of themes arising from the lived experiences of both patients and relatives.

Conclusion

Our study reveals that patients and relatives might experience multidimensional support needs throughout their euthanasia trajectories. Our findings suggest that they experience their euthanasia trajectories as explicitly social-existential in nature. As their support needs essentially correspond with those experienced in other trajectories at the end of life, support for patients and relatives in euthanasia practice might benefit from a palliative care approach.

Several relevant implications for clinical practice and future research can be voiced. First, our findings offer valuable insights that can inform HCPs, educational curricula, practice tools –e.g., guidelines for euthanasia-, and training programs on which support needs regarding euthanasia they can focus on improving the euthanasia experiences and outcomes of patients and relatives. Secondly, our study provides empirical evidence for key components that should be included in a needs-oriented approach to care or support for euthanasia practice, such as a person-centered approach. Thirdly, HCPs should pay attention to the non-medical support needs of patients and relatives, with particular attention to their social and existential needs. In this regard, promising approaches to facilitate social interaction between patients and relatives throughout their euthanasia trajectories may include family therapeutic methods, family group discussions, and nurse-delivered dyadic interventions.[48–51] Following this, future research could investigate the most effective type of support to fulfill the social and existential support needs of patients and relatives in euthanasia practice, given the current lack of research on this topic.

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Chapter 5

Experience-based good practices in euthanasia: a qualitative study of the lived experiences of healthcare professionals

Stijn Vissers, Joni Gilissen, Joachim Cohen, Luc Deliens, Freddy Mortier, Kenneth Chambaere*, Sigrid Dierickx*

*Joint final authors

Submitted

Abstract

Background: Euthanasia as an end-of-life option is legally accessible in an increasing number of jurisdictions worldwide. Patients, relatives, and healthcare professionals (HCPs) involved in euthanasia can experience undesired outcomes. This may imply that the support they receive is suboptimal. While applying good practices can be a worthwhile approach to improve support, we have little guidance on good practices in euthanasia practice. Moreover, HCPs with lived experiences might have developed good practices, which can be useful to share across the medical field. Therefore, our study aimed to explore the good practices that HCPs deploy and identify in their euthanasia practices.

Methods: We performed a qualitative study in Flanders (Belgium) in 2022 with HCPs having lived experience with euthanasia practice using semi-structured interviews (N=26), focus groups (N=7), and an expert panel discussion (N=1). Participants were recruited using purposive and snowball sampling. We performed an interpretative thematic analysis.

Findings: We analyzed the interview data from 64 HCPs. We identified seven themes in relation to the good practices that HCPs deploy and identify in euthanasia: 1) patient-centeredness, 2) family-centeredness, 3) safeguarding the psychological well-being of HCPs, 4) managing expectations of patients and relatives, 5) carefulness, 6) multidisciplinary approach, and 7) compassionate, proactive, and communicative HCPs.

Conclusion: Our findings show that HCPs apply various good practices in euthanasia. These good practices relate to specific methods, techniques, and attitudes. Our study suggests that HCPs can improve their euthanasia practices by considering a non-medical approach that pays attention to social, existential, and psychological aspects of euthanasia practice.

Introduction

In the last decade, assisted dying has become an increasingly prevalent medical practice in several jurisdictions worldwide, home to approximately 300 million people.[1] Most likely, these numbers will continue to increase as other jurisdictions, such as Germany and Scotland, are currently debating and drafting legal frameworks for assisted dying.[2,3]

Assisted dying comprises two practices: physician-assisted suicide and euthanasia. In physician-assisted suicide, a healthcare professional (HCP), typically a physician, prescribes or provides lethal medication to a patient on their voluntary request to use to end their own life.[1] In euthanasia, a HCP intentionally ends a person's life on their voluntary request by administering lethal medication.[1]

Persons requesting euthanasia (hereafter ‘patients’), their relatives, and healthcare HCPs may experience euthanasia as a complex and multifaceted practice.[4] This can lead to social, psychological, existential, medical-technical, and practical difficulties and challenges encountered throughout the euthanasia trajectory.[5–12] This trajectory encompasses 1) the period prior to the performance, when the patient holds an explicit desire for euthanasia, they formally requests euthanasia, the attending physician assesses the patient’s eligibility for euthanasia, and the performance of euthanasia is being prepared; 2) the day of performance; and 3) the period following the performance.[13]

To address these difficulties and challenges, scholars have recommended improving the care and support provided throughout the euthanasia trajectory, e.g., by identifying and implementing good practices in euthanasia.[7,9,14–18] The term ‘good practice’ refers to either a method, technique, or attitude that a HCP deploys because they experience that it leads to better or high-quality outcomes for either patients, relatives, or HCPs (themselves included) as compared with other alternatives.[19] Although good practices could improve euthanasia practice, identifying them has received limited research attention. A better understanding of the good practices in euthanasia has several benefits. Good practices could be included in guidelines for HCPs and may guide them in supporting patients and relatives throughout their euthanasia trajectories. Therefore, the present study aimed to explore healthcare professionals’ good practices in euthanasia.

Methods

Research question and definitions

The research question of our study is: ‘Which good practices do healthcare professionals deploy and identify in their euthanasia practices?’.

Research paradigm and study design

We applied a multimethod, qualitative design to explore HCPs’ good practices in euthanasia using semi-structured interviews, focus groups, and an expert panel discussion.[20] Adopting social constructionism, we presumed that individuals construe and give meaning to their own good practices in euthanasia through their lived experiences.[21]

This design is well-suited for capturing the complexity of certain social phenomena, such as euthanasia practice.[22] Moreover, it strengthens the validity of our research findings, as multiple methods may reveal distinct angles and nuances not detectable with a single method.[22]

This article follows the Consolidated Criteria for Reporting Qualitative Research (COREQ).[23]

Study setting and population

We conducted this study in Flanders and Brussels, Belgium, where euthanasia is lawful under strict conditions.[2] Our research population encompassed HCPs having lived experience with euthanasia practice. The specific inclusion criteria for research participants were: 1) being an HCP, 2) holding experiential knowledge about euthanasia practice through personal involvement in providing care or support to a patient with an explicit desire for euthanasia or their relatives, 3) being comfortable with being interviewed in Dutch, 4) working in Flanders or Brussels (Belgium), 5) being 18 years or older, and 6) having provided informed consent to participate in the study. We included a seventh criterion for the expert panel discussion: holding an advanced level of expertise in a particular area of euthanasia practice.

Sampling and recruitment

We used purposive and snowball sampling to obtain a heterogeneous sample across care settings, sex, age, professions, and health specialties, with a particular focus on physicians, nurses, psychologists, and social workers. Included participants were asked to identify other suitable participants.

Participants were recruited across Flanders and Brussels (Belgium) using mailing lists, newsletters, social media platforms of healthcare organizations, health professional associations, and the professional network of the End-of-Life Care Research Group.

Data collection

From January to September 2022, we conducted semi-structured interviews with physicians and focus groups with nurses, psychologists, and social workers. Due to COVID-19 measures, we collected these data online by video call using Whereby (Whereby.com) and Zoom. HCPs who could not attend the focus groups could participate in a semi-structured interview. We developed an interview guide that included the following topics: 1) lived experiences with euthanasia practice, 2) difficulties and challenges experienced in euthanasia practice, 3) good practices in euthanasia practice, and 4) support needs in euthanasia practice. Data were collected by SV (MSc, Ph.D. candidate, male), JG (Ph.D., senior researcher, female), KC (Ph.D., senior researcher, male), and SD (Ph.D., senior researcher, female), who are all researchers with previous experience in conducting qualitative health research. SV conducted 17 semi-structured interviews, and SD conducted one. For the focus groups, SV was the principal moderator, with SD or JG acting as assistant moderators and note-takers. In addition, we took field notes to document the context and our reflections to inform future data collection and analysis.

On 29 June 2022, we performed an online expert panel discussion via Zoom with HCPs having advanced expertise in euthanasia, using a focus group approach. The panel discussion consisted of two parts. In the first part, moderated by KC, we presented the preliminary results from the interviews and the focus groups to panel members, who were then asked to discuss these in-depth. In the second part, panel members were divided into three homogenous groups (Zoom break-out sessions) according to their expertise to discuss in-depth their own good practices in euthanasia. SV, JG, and KC moderated these discussions.

Interviews, focus groups, and the expert panel discussion were audio recorded and transcribed verbatim. We used inductive thematic saturation to guide our data collection, defining saturation as the point at which five consecutive interviews or focus groups were conducted without the emergence of new meaning related to the themes of support needs.[24]

Data analysis

We conducted an interpretative thematic analysis in several phases.[20] First, SV and SD familiarized themselves with the data by repeatedly reading the transcripts and field notes for patterns and meaning.

Second, SV and SD independently identified initial codes inductively from seven transcripts. These initial codes were compared and discussed to develop a unified coding framework. SV used this framework to analyze the remaining transcripts, adapting the framework accordingly. Next, SV and SD merged codes with similar meanings into subthemes upon consensus. Lastly, in several group meetings, all authors reviewed the subthemes and merged them into themes upon consensus. NVivo 12 was used to analyze the data. Following an inductive thematic saturation model, we concluded that saturation was reached after 80% of all transcripts were analyzed.[24]

Ethical considerations

The Ethics Committee of the Brussels University Hospital and Vrije Universiteit Brussel approved our study (BUN 143202100057; 15 September 2021). We assigned pseudonyms to all participants in the transcripts and removed any identifying information. Additionally, we obtained written or oral informed consent from all participants.

Results

Sample characteristics

The final sample comprised 64 HCPs: 25 physicians, 18 nurses, 9 psychologists, 7 social workers, and 5 case managers (Table 1). Fourteen participants were HCPs with advanced expertise in a particular area of euthanasia practice. The semi-structured interviews had a mean duration of 72 minutes (range 43-103 minutes), the focus groups of 127 minutes (range 95-133 minutes), and the expert panel discussion of 122 minutes.

Table 1. Participant characteristics of healthcare professionals (N=64)

	Interviews* (N=26)	Focus groups (N=7)	Expert panel (N=1)	Total N (%)
No. of participants	26	24	14	64 (100)
Sex				
Female	16	17	6	39 (59)
Male	10	7	8	25 (41)
Age group (years)				
< 30	3	1	0	4 (6)
30 - 45	6	10	3	19 (30)
46 - 60	13	8	4	25 (39)
> 60	4	5	7	16 (25)
Profession				
Physician**	18	0	7	25 (39)
Nurse	2	12	4	18 (28)
Psychologist	3	6	0	9 (14)
Social worker	0	6	1	7 (11)
Case manager	3	0	2	5 (8)
Main care setting				
Home	17	11	8	36 (56)
Hospital	9	13	6	28 (44)

* Semi-structured interviews

** We conducted semi-structured interviews with 13 general practitioners, 3 medical oncologists, and 1 gastroenterologist. In the expert panel, we included 3 general practitioners, 1 anesthetist, 1 neurologist, 1 geriatrician, and 1 surgeon.

Thematic findings

We identified seven themes: 1) patient-centeredness, 2) family-centeredness, 3) safeguarding the psychological well-being of HCPs, 4) managing expectations of patients and relatives, 5) carefulness, 6) multidisciplinary approach, and 7) compassionate, proactive, and communicative HCPs (Figure 1). Each theme refers to an ‘overarching good practice’ (our term), which reflects a broad principle or approach underpinning various ‘specific’ good practices. A ‘specific’ practice is a practice that a HCP directly applies in their euthanasia practice. Overall, we found 28 specific good practices that HCPs deploy and identify in their euthanasia practices. It should be noted that these 28 specific good practices reflect the findings from all participants’ narratives of good practices. As such, these 28 specific good practices may differ from the total number of good practices within individual euthanasia cases. In other words, good practices deployed and identified by one HCP do not necessarily imply that other HCPs identify and deploy them as good practices in their euthanasia cases. Furthermore, exemplary quotes are provided in Table 2.

FIGURE 1. **28 specific best practices were identified that healthcare professionals (HCPs) identify and deploy in their euthanasia practices**

Patient-centeredness	Family-centeredness	Safeguarding the psychological well-being of HCPs	Managing expectations of patients and relatives	Carefulness	Multidisciplinary approach	Compassionate, proactive, and communicative HCPs
Continuously assessing and meeting patients' needs and preferences	Continuously assessing and meeting relatives' needs and preferences	Self-care	Developing euthanasia literacy in patients and relatives	Continuity of support	Multidisciplinary collaboration	Being a compassionate HCP
Safeguarding patient autonomy	Actively involving relatives	Special attention to the psychological well-being of colleagues	Developing euthanasia preparedness in patients and relatives	Professional preparedness for the performance of euthanasia	Clear communication between HCPs	Being a proactive HCP
Psychosocial support for patients	Special attention to children and young adults		Establishing clear arrangements with patients and relatives	Carefulness in assessing eligibility for euthanasia	Consulting and involving special expertise	Being a communicative HCP
Spiritual-existential support for patients	Facilitating communication between patients and relatives			Medical-technical carefulness		
	Psychosocial support for relatives			Serenity during the performance of euthanasia		
	Anticipatory grief and bereavement care for relatives			Professional knowledge and skills about euthanasia		
	Spiritual-existential support for relatives					

Table 2. Participants' quotes of their good practices in euthanasia

Patient-centeredness	
Safeguarding patient autonomy	*"As a general practitioner (GP), I maintain a therapeutic relationship with my patients and often know their families. Even after a patient passes away, they remain my patient. However, I always prioritize the patient's wishes regarding euthanasia. I don't call the family to tell them that s/he has requested euthanasia. I leave it up to the patient to decide whether or not to involve them. I encourage patients to invite their children, but ultimately, it's their choice to inform their family and have a family discussion. I want to supervise that discussion, but it's up to the patient to inform their children that they have requested euthanasia. In one case, a patient requested euthanasia without wanting their family to know, despite my suggestion that it could have positive outcomes. I respected his decision as their GP and proceeded without involving their family."* -General practitioner-
Psychosocial support for patients	*"Some HCPs still believe that once a patient has decided to pursue euthanasia, there is no longer a need for psychosocial support as their unbearable suffering cannot be relieved. On the contrary, it is crucial to provide psychosocial support when a patient expresses their desire for euthanasia. This can help alleviate some of the emotional distress and even provide comfort as euthanasia is quite difficult to manage emotionally."* -Nurse-
Family-centeredness	
Special attention to children and young adults	*"I believe that children should be allowed to be present during euthanasia if they wish, provided they have been given comprehensive information about the process. I always involve children. In the last case, I sat next to a ten or eleven years old girl and explained step by step what was happening. 'They inject a barbiturate, similar to the anesthesia used during surgery. This puts the patient to sleep, and they don't remember anything. They no*

	longer feel anything and can no longer hear us. Eventually, their breathing will stop while their heart continues to beat. Then their heart will stop.' By providing this technical information, I was able to offer reassurance to the child and help dispel any unnecessary fantasies they may have had about the process. Children's imagination is always bigger than reality, of course. So if you forbid them from being in the room, they will imagine unrealistic scenarios next door." -Psychologist-
Facilitating communication between patients and their relatives	*"It's crucial for the relatives of a patient to accept that euthanasia was the best solution for their loved one, even if they may have had different feelings about it. I always remind patients during the assessment to talk to the people they love, to help them understand how bad it is and why they have made this decision. It can help their loved ones move on and cope with the loss. People often appreciate having a moderator to deal with such heavy topics, to help bridge the communication between the patient and their family. I find it valuable to fulfill this bridging function, especially when families disagree with the patient's request."* -General practitioner-
Anticipatory grief and bereavement care for relatives	*"The period leading up to euthanasia can be very intense, with much support for both the patient and their family. After the patient's euthanasia, the family may feel like they're falling into a black hole. It can be a challenge, especially because the days leading up to the performance are often filled with plans to have their last nice moments together. Sometimes the patient is still doing well compared to other terminal patients, so it can feel like they're taken away too suddenly by the performance of euthanasia. It's a very abrupt transition from a very intense period of living together to suddenly being alone. This is why I provide grief support for the family, as it is so important."* -General practitioner-

Safeguarding the psychological well-being of healthcare professionals	
Applying self-care	*“It's important to set boundaries for yourself when it comes to euthanasia. If it doesn't feel right, you shouldn't do it, because it can have negative consequences for you later on. Compared to my colleagues, I feel less need for debriefing or intervention after the performance because I have less doubt about whether we did the right thing. On the other hand, some doctors may feel pushed beyond their limits to perform euthanasia. When you agree to a patient's request for euthanasia, you must also monitor your self-care closely. It's a disaster if you have to tell your patient and their family that you can't go through with it, but you have to prioritize your well-being because you have to live with it if you have ended someone’s life.”* -Oncologist-
Special attention to the psychological well-being of colleagues	*“After the euthanasia is carried out, sometimes, if the colleague who performed the euthanasia is someone I am close to, I will offer a hug, pat on the back, or words of encouragement such as ‘You did well. Are you okay? Don't hesitate to call me if you need to talk.’"* -Nurse-
Managing expectations of patients and relatives	
Developing euthanasia literacy in patients and relatives	*“The lack of knowledge is often the reason for the family’s fear and uncertainty. It's understandable to be afraid of the unknown. However, in most cases, a loved one has consciously requested euthanasia. I find that being transparent and explaining the euthanasia procedure brings comfort to family members and loved ones. This includes informing them about what to expect of the process and the outcomes. To help with this, our hospital has created a brochure outlining the full procedure. This includes examples of written requests, what modalities need to be included, and information on when and how to request euthanasia. We’ve compiled all our information into one brochure to help people understand the process.”* -Psychologist-

Establishing clear arrangements with patients and relatives	*"We make it clear from the outset that the euthanasia process is never rushed and that we need to take our time. We understand that it's difficult for everyone involved and requires us to go beyond our normal ethical boundaries as doctors. […] They have the right to request euthanasia, but we HCPs are responsible for evaluating the situation and determining whether it's appropriate to proceed. If we determine that it can't be done because certain conditions are not being met, we explain this clearly to the patient and their loved ones. By doing so, we help them understand our decision and avoid potential anger or frustration down the road."* -Oncologist-
Carefulness	
Continuity of support	*"Most physicians who have known their patients for years agree to carry out the procedure. However, some physicians categorically refuse to be involved in euthanasia, and I respect their decision. Ideally, it's best when the patient's GP is willing to start the euthanasia procedure and be the attending physician. But sometimes, it's not that simple. I never argue with a physician about their decision not to be involved. If they want to explain why, that's up to them. What's important is that the physician takes responsibility for finding a colleague willing to carry out the procedure. Leaving the patient out in the cold is not an option. So, I always encourage the physician to find another attending physician for the patient. Together, we will search for another attending physician to take care of the request."* -Nurse-
Professional preparedness for the performance of euthanasia	*"Proper preparation is essential for carrying out euthanasia. It's important to ask all the necessary questions beforehand: What steps must be taken? What equipment and medications are required, and in what doses? Which patients require adjustments to their medication? The medication itself can also be challenging, as it may need to be ordered in advance from a pharmacy. If the medication is unavailable, we may need to call other*

	pharmacies until we find one that can supply it. It's important to perform euthanasia as well as possible, as there is only one chance to do it right." -General practitioner-
Medical-technical carefulness	*"I often work with attending physicians to determine the correct medication dosage. I notice that the attending physician is often unsure about the dosage, such as how many ampoules to use and how much should be administered in cc. In most cases, a nurse will insert the intravenous access route beforehand. However, there have been situations in which I had to do it if the attending physician was too nervous or inexperienced. During the performance, I usually kneel beside the physician to ensure that the medication is administered in the correct order. Proper labeling of the syringes is crucial, especially since the barbital is yellowish, and the physiological water is colorless. This prevents any mix-ups or mistakes. If a doctor insists on doing it alone, I remind them that they can always ask for my support. It's never safe to do it alone."* -General practitioner-
Multidisciplinary approach	
Multidisciplinary collaboration	*"We respond to all euthanasia requests as a team. We have psychologists working together with our doctors, and we find multidisciplinary collaboration essential. If the ward nurses are unwilling to assist in the performance, I can always contact the palliative team for additional support. If a euthanasia request arises, we discuss it together and determine how we feel about the situation."* -Oncologist
Consulting and involving special expertise	*"When it comes to determining a patient's terminality, we sometimes need to rely on other experts. It's challenging to estimate survival time for patients. However, there is a general consensus that terminality refers to the range of zero to six months. We are aware that the Federal Commission for the Control and Evaluation of Euthanasia uses these concepts. However, it's not always easy to predict how long someone will live, especially in non-*

	oncological illnesses or frailty cases. While it's often straightforward in oncology cases, it can be impossible to determine in other cases.“ -Geriatrician-
Compassionate, proactive, and communicative healthcare professionals	
Being a compassionate HCP	*“I've realized that support can come in various forms, not just on a meta-level such as existential or spiritual guidance. Sometimes it's the little things that can make a big difference in how patients experience the process of euthanasia. For example, I often use small touches, such as laying a hand on someone's shoulder, to provide comfort and reassurance during the process. It's not always about big hugs but rather about being present. Being close to the patient does make them feel better.”* -Case manager-
Being a proactive HCP	*“Being proactive and not waiting for patients and families to ask for support can be helpful, for instance, offering the family to connect with a psychologist without them having to initiate the request. Some family members may be hesitant to ask for support or believe that psychologists are only called in for serious psychological issues or therapy when they can provide valuable support through conversation. By anticipating support and offering it proactively, many potential problems can be avoided.”* -General practitioner-

Patient-centeredness

Continuously assessing and meeting patients' needs and preferences. Most participants perform this throughout the euthanasia trajectory to ensure that needs and preferences are effectively addressed and to provide customized, needs-based support. From the participants' experiences, this leads to an increased quality of life in patients. Continuous assessment is deemed essential as needs and preferences may change.

Safeguarding patient autonomy. Participants strive to achieve this by maximizing patient decision-making and giving them control over their euthanasia trajectories. That includes, for example, allowing patients to determine the timing of performance, obtaining patient consent on which HCPs can be involved in their euthanasia trajectories, and allowing patients to decide the extent of family involvement in their euthanasia trajectories.

Psychosocial support for patients. Participants apply this as they experience that it leads to better outcomes in various aspects of the euthanasia trajectory, for example, preparing patients for death, protecting and improving patients' mental well-being, developing emotional resilience and strategies to cope with psychological distress, offering emotional guidance, providing comfort for specific concerns, discussing the emotions of the patient, and managing difficult periods, e.g., the prolonged waiting period for assessing the euthanasia request in patients with a non-terminal condition, or the period after the request has been denied. Participants report that they often involve psychologists and palliative care teams in providing psychosocial support. Some participants provide psychosocial support by conducting multiple conversations with patients throughout their euthanasia trajectories.

Spiritual-existential support for patients. The majority of participants perform this, mainly as a way to address patients' existential concerns and questions, and to pay attention to their life values and beliefs. In this regard, some participants encourage patients to organize a farewell ritual before the performance of euthanasia. Several participants volunteer to serve as facilitators in such rituals, while taking part in them as well.

Family-centeredness

Continuously assessing and meeting relatives' needs and preferences. Most participants carry this out in their euthanasia practices. They experience that an individual assessment for relatives is necessary because their needs and preferences differ from those of patients. This assessment is also viewed as an opportunity to address relatives’ questions and concerns about euthanasia and to create a trusting relationship.

Actively involving relatives. Most participants apply this in their euthanasia practices, for example, through family conversations. They experience that involvement may facilitate the acceptance of euthanasia, mitigate (anticipatory) grief reactions, and resolve social conflicts between patients and relatives before the performance. In addition, several participants actively involve relatives to ascertain that they are not pressuring patients to request euthanasia.

Special attention to children and young adults. Some participants approach children and young adults being close to the patient differently than adults, since they might react differently to euthanasia and death. This approach is adapted to their level of maturity and includes, for example, using plain language, and tailoring their involvement to their individual needs.

Facilitating communication between patients and relatives. The majority of participants practice this, as communication between patients and relatives can be challenging and tense in euthanasia practice. For example, participants advise patients to communicate their personal motives for requesting euthanasia to their relatives. As such, they aim to empower patients and relatives to openly communicate their emotions and thoughts to each other prior to the performance, partly to avoid any regrets or difficulties during the grieving process following the performance.

Psychosocial support for relatives. Participants provide this throughout the euthanasia trajectory for similar reasons as for patients. Additionally, it also functions as a means of determining whether relatives support the performance of euthanasia. Some participants believe that relatives strongly opposed to euthanasia require more intensive psychosocial support to enhance their mental well-being, ideally provided by a psychologist. For relatives agreeing with the performance, they experience that less intensive psychosocial support is sufficient, and therefore, can be provided by a range of HCPs, such as attending physicians and nurses. Moreover, most participants believe that an additional HCP supporting the attending physician is needed on the day of the performance to provide psychosocial support to relatives.

Anticipatory grief and bereavement care for relatives. Participants use anticipatory grief care to address potential issues with the anticipated loss and its emotional impact prior to the performance of euthanasia. Bereavement care is provided after the performance to help relatives adjust to life without the patient. Moreover, some participants give relatives the option to reconvene with them after the performance to discuss and reflect upon the euthanasia trajectory, to assess their bereavement needs, and to evaluate the presence of complicated grief.

Spiritual-existential support for relatives. Participants note that some relatives have a strong need to perform spiritual practices throughout the euthanasia trajectory, such as carrying out rituals and traditions honoring the patient. Therefore, they provide this support to guide relatives in these spiritual practices to offer them comfort and peace. Furthermore, several participants encourage relatives to perform a farewell ritual by highlighting its benefits.

Safeguarding the psychological well-being of healthcare professionals

Self-care. Participants perform self-care as they experience that being engaged in euthanasia practice may have a psychological impact. First, this involves setting moral boundaries for themselves by not being involved in those euthanasia trajectories conflicting with their moral values, and disengaging when they notice that euthanasia is no longer an appropriate option for the patient. Second, this also involves practicing specific self-care activities after the performance of euthanasia to decompress and facilitate closure, such as socializing with colleagues or friends.

Special attention to the psychological well-being of colleagues. Some participants perform this as they experience that being involved in euthanasia practice as a HCP can have a psychological impact. This includes, for example, allowing colleagues to refuse involvement for ideological reasons and disengage from the euthanasia trajectory at any time, acting as a buddy or confidant for colleagues, and organizing debriefings to discuss psychological challenges that colleagues may face in relation to practicing euthanasia.

Managing expectations of patients and relatives

Developing euthanasia literacy in patients and relatives. Participants use this to instill patients and relatives with knowledge about euthanasia practice so they can grasp and navigate their euthanasia trajectories and anticipate common misunderstandings of euthanasia. This includes, for example, explaining legal requirements for euthanasia, informing that patients need to be mentally competent to receive euthanasia, highlighting that patients experiencing tiredness of life without incurable severe illness are not eligible for euthanasia, and instructing how to draft a written request for euthanasia.

Developing euthanasia preparedness in patients and relatives. Most participants practice this to ensure that patients and relatives are mentally prepared to face the performance of euthanasia. This is accomplished by, for example, addressing their concerns and questions about the performance, providing all (non-) medical information about the performance, addressing their wishes and expectations regarding the performance, and making mutual agreements on the performance.

Establishing clear arrangements with patients and relatives. Participants practice this throughout the euthanasia trajectory. It helps to ensure that they are on the same page regarding the provision of support, to correct misperceptions of the process toward euthanasia, and to anticipate expectations about their euthanasia trajectories that cannot be met, for example, performing the euthanasia assessment in one or two days.

Carefulness

Continuity of support. Participants view this as a good practice as patients often receive fragmented support from different providers throughout their euthanasia trajectories. This includes, for example, continuing to guide patients after their requests have been denied or withdrawn, providing patients with the contact details of other HCPs in the context of referral, and following up with the patient as their general practitioner (GP) when another physician assesses the request.

Professional preparedness for the performance of euthanasia. Participants define this as holding a state of readiness, including mental preparation, and developing the adaptability to manage potential hazards and unexpected events during the (day of the) performance of euthanasia. Participants experience that this can help HCPs to increase their sense of control, thereby reducing the potential psychological impact of the performance.

Carefulness in assessing eligibility for euthanasia. Participants say they practice this by adopting a comprehensive approach with attention to detail. They report considering all relevant factors and making decisions in the best interests of patients and relatives before granting the request. Specific actions that they undertake to ensure carefulness include, for example, involving the patient’s GP, examining the patient’s complete medical history instead of only recent medical records, and denying the request if the euthanasia request assessment of the independent second or third physician (which is required by law) concludes that the patient does not meet eligibility for euthanasia.

Medical-technical carefulness. Participants apply this during (the day of) the performance, taking specific medical-technical actions to prevent accidents and minimize risks to achieve a successful performance. Such actions include, for example, administering drugs intravenously, inducing sleep in the patient before administration, having an experienced professional place the intravenous line or catheter for the drugs, such as a palliative care nurse or an anesthesiologist, and performing euthanasia in the presence of a colleague who can also monitor the medical-technical carefulness.

Serenity during the performance. Some participants seek to ensure this as the performance can be tense for patients and relatives. The aim of this serenity is to establish calmness and tranquility, making them feel comfortable with the performance. This is done, for example, by having music played during the performance, advising relatives being opposed to euthanasia not to attend during the critical moment of the performance, and informing relatives they may leave the room if needed.

Professional knowledge and skills about euthanasia. Most participants experience that HCPs with profound experience with and knowledge of euthanasia legislation, request assessment, actual performance, and support for patients and relatives in euthanasia practice, achieve better outcomes than those without such experience and knowledge.

Multidisciplinary approach

Multidisciplinary collaboration. The majority of participants collaborate with HCPs from various disciplines, such as medicine, nursing, social work, and psychology. This collaboration is used in, for example, providing psychosocial support for relatives, the medical-technical preparation of the performance, and assessing the patient's eligibility for euthanasia. Participants experience that multidisciplinary collaboration improves their euthanasia practices as it can address challenges that are difficult to manage alone.

Clear communication between HCPs. Participants define this as straightforward, uncomplicated, and easily understandable communication. They consider this essential to ensure fluent euthanasia trajectories. It is particularly emphasized as a good practice in the interaction between the attending physician and the second or third physician during request assessment, in making mutual agreements for the performance of euthanasia, in exchanging professional opinions about the patient's eligibility for euthanasia, and in deciding and establishing the support for patients and relatives.

Consulting and involving special expertise. Most participants apply this in euthanasia practice, particularly when they lack particular expertise to overcome specific challenges. This includes, for example, consulting a psychiatrist to evaluate the patient's unbearable suffering, involving a neurologist for evaluating and monitoring the mental capacity of a patient with a neurodegenerative disorder, and involving palliative care experts to provide psychosocial support to patients and relatives.

Compassionate, proactive, and communicative healthcare professionals

Being a compassionate HCP. Participants view this as holding empathy and an open-minded attitude. They notice that patients and relatives trust compassionate HCPs more and are being more receptive to them. This, for example, can lead to sharing more personal information while assessing eligibility for euthanasia.

Being a proactive HCP. Some participants experience this as a good practice, defined as proactively preventing and anticipating problems that patients and relatives might encounter during their euthanasia trajectories. They consider this a good practice because patients and relatives often address their problems too late, i.e., after any negative experiences.

Being a communicative HCP. Participants define this as expressing themselves clearly and listening actively to patients and relatives. This results in better outcomes as it reduces misunderstandings and conflicts in euthanasia practice.

Discussion

Main findings

Based on the qualitative interview data from 64 HCPs, we found that HCPS identify and deploy 28 specific good practices in their euthanasia practices. These specific good practices relate to seven principles ('overarching good practices'): 1) patient-centeredness, 2) family-centeredness, 3) safeguarding the psychological well-being of HCPs, 4) managing expectations of patients and relatives, 5) carefulness, 6) multidisciplinary approach, and 7) compassionate, proactive, and communicative HCPs.

Interpretation of findings

We found that HCPs identify and deploy a multitude and diversity of good practices in euthanasia that, from their experiences, lead to better outcomes and/or higher quality of practice. Some of the identified good practices resonate with the findings of a study on HCPs' experiences of facilitators to providing high-quality clinical care in medical assistance in dying (MAID) practice in Canada.[14] Analogously, this study found that 'emotional support for patients and families' and 'interprofessional collaboration' lead to higher quality of MAID practice from HCPs' experiences.[14] Moreover, some of our identified good practices correspond with the qualities of good death defined by patients accessing MAID, namely, 'respecting autonomy', 'preparing for good death', and 'sense of connectedness'.[12]

Furthermore, according to participants, a patient-and-family-centered approach leads to better outcomes in euthanasia practice. Hence, our results support the increasing consensus among scholars that person-centeredness is the way forward in assisted dying practice.[7,9,17,25] However, reconciling family-centeredness with patient-centeredness may be challenging in practice as patient needs and preferences can conflict with those of their relatives.[9] As stated by our research participants, a solution to that may lie in facilitating clear communication between both parties and managing their expectations. Managing expectations seems particularly important, considering that a small discrepancy between prior expectations and actual outcomes is associated with high patient and family satisfaction.[26,27]

A noticeable finding is that many good practices relate to interpersonal and people skills, for example, providing spiritual-existential support, paying particular attention to children and young adults, and managing expectations. These good practices may require a considerable investment of time and specific expertise. These findings support the Canadian Medical Education Directions for Specialists (CanMEDS) framework (i.e., a framework of physician competencies), which highlights the importance of physicians being collaborators and communicators, among other abilities, to meet patients' needs adequately.[28] Hence, our study suggests that, from a professional perspective, euthanasia should not be approached solely as a medical-technical practice, but also as a social-relational practice. In this regard, previous studies speak of euthanasia practice as an (inter)relational reality or complexity.[29,30]. Euthanasia as an social-relational practice is further mirrored in the fact that several good practices relate to a social attitude, such as compassionate HCPs. Compassionate HCPs, indeed, may positively influence the health outcomes of patients at the end of life, as they seek to understand and accept the patient as a whole.[31] Consequently, cultivating and training compassion among HCPs seems appropriate to ensure high-quality euthanasia practice for patients, but also for HCPs themselves as compassion, in return, may decrease their levels of distress related to euthanasia practice.[31,32]

Interestingly, some good practices tie in with case management practices, such as continuity of care and setting clear arrangements with patients and relatives. Case management is a healthcare approach that involves the collaboration of several HCPs to assess, plan, implement, coordinate, monitor, and evaluate the care and support required to meet a person's needs.[33] It is especially effective for individuals with complex health needs, such as terminal cancer and frailty.[34] Thus, applying case management as good practice in euthanasia is not surprising as patients and relatives may hold complex needs throughout their euthanasia trajectories as well.[13,35] Using case managers may be a valuable strategy to ensure fluent euthanasia trajectories as they can facilitate patient and family referrals, reduce the administrative workload for attending physicians, and are generally more effective in obtaining accurate patient information.[36]

Over recent years, research has increasingly paid attention to the impact of being involved in assisted dying on HCPs.[37] As such, studies have revealed that involvement can adversely affect the psychological well-being of HCPs, resulting in moral distress, feelings of loneliness, anxiety, and emotional overload.[8,14,38–44] Our findings show that HCPs use various strategies to cope with the potential adverse impact of euthanasia, namely, self-care and paying attention to the psychological well-being of colleagues. While the practice of self-care extends prior studies[37], being mindful of the mental well-being of coworkers as a good practice is rather a novel finding. This demonstrates that HCPs situate the responsibility for safeguarding their psychological well-being with themselves and their professional environment. However, self-care and being mindful of the well-being of colleagues require forms of (self-)awareness, (self-)compassion, and altruism at the individual level.[45] Therefore, it is advisable to implement preventive measures simultaneously at the organizational-structural level in the professional environment, for example, by providing psychological counselling services to HCPs engaged in euthanasia practice. In this way, their organizations also bear the responsibility to safeguard the psychological well-being of their HCPs.

Study strengths and limitations

The first strength of this study is that we included a wide variety of research participants from different disciplines, which is particularly noteworthy for a qualitative study. Second, our study used a multi-perspective approach elaborating upon the lived experiences of physicians, nurses, social workers, psychologists, other HCPs, and experts in euthanasia practice. This approach has enriched our data considerably. Third, several strategies were used to ensure the rigor and trustworthiness of our research: 1) investigator triangulation, 2) continuous reflection, and 3) obtaining data saturation.[46]

Regarding the study limitations, first, it cannot be ruled out that we captured some normative-based good practices instead of experience-based ones. To minimize this as much as possible, we only included research participants having lived experience with euthanasia practice. Second, we reported good practices from the perspectives of experiences of HCPs and experts; however, these practices may not result in actual favorable outcomes in the experience of patients and relatives. Third, as most participants were mainly active in the home setting, we could have missed some good practices on euthanasia in the hospital setting. Fourth, some social desirability may have occurred, for example, in the focus groups, as participants may have felt compelled to demonstrate their good practices to their peers.

Implications for practice, policy, and research

The good practices identified can be used by those involved in euthanasia to improve outcomes for patients, relatives, and caregivers. Moreover, they can inform quality improvement initiatives for euthanasia, such as practice guidelines and training for HCPs.

Our findings may support public health policy in developing and achieving quality and monitoring standards for assisted dying practice. Furthermore, they can provide policymakers with evidence-based information on specific actions and practices that could be encouraged to obtain optimal outcomes in euthanasia practice. In this respect, we recommend applying our identified good practices to guide patients and relatives in their euthanasia trajectories.

Future research could investigate the good practices that patients and relatives identify in their euthanasia trajectories and to what extent these correspond to our findings. This may lead to establishing an integrated framework of good practices in euthanasia. Furthermore, it would be interesting to conduct an implementation study that integrates one or more of the identified good practices into euthanasia practice, such as family-centered support. It would also be interesting to examine further the effectiveness of the implemented good practice, for example, by conducting an interventional study evaluating the effect of family-centered support on the quality of life or grief reactions of relatives engaged in euthanasia practice.

Conclusion

Our study shows that HCPs deploy a range of good practices in euthanasia, of which many relate to non-typical medical actions or interventions and some to a specific attitude of the HCPs involved. Our findings suggest that obtaining high-quality euthanasia practice also involves paying attention to its social, existential, organizational, and psychological dimensions. HCPs and health services seeking to improve euthanasia outcomes could consider adopting a patient-and-family-centered and multidisciplinary approach.

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PART III

CONTROL AND SUPPORT IN CONTINUOUS DEEP SEDATION UNTIL DEATH: CURRENT PRACTICES AND POTENTIAL FOR IMPROVEMENT

Chapter 6

Control measures for continuous deep sedation until death: a framing analysis of the views of physicians

Stijn Vissers, Lenzo Robijn, Sigrid Dierickx, Freddy Mortier, Joachim Cohen, Luc Deliens, Kenneth Chambaere

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Abstract

Physicians have been subject to increasing external control to improve their medical practice and scholars have theorized extensively about their opposition to such control. However, little empirical attention has been paid to the views and reasoning which lie behind this opposition. An in-depth understanding is necessary for enhancing the effectiveness and efficiency of external controls and continuous deep sedation until death (CDS) is an interesting case in this regard. This study aims to explore how physicians frame control measures for CDS. We conducted 47 semi-structured interviews with Belgian physicians in 2019. A qualitative framing analysis was performed to analyze their views and reasoning. This study reveals that physicians approach CDS practice and control measures with different emphases. Controlling by mechanisms of professional self-regulation and state governance are put forward as appropriate means to improve CDS practice. Policymakers should take into consideration physicians' frames in order to develop sound control measures.

Introduction

Medical practice in Western countries has been subject to increasing professional regulation in recent decades, for instance auditing, medical guidelines, protocols, medical standards and quality indicators, and incident report systems have emerged as improvement initiatives from inquiries into medical practice and health care systems.[1] Medical professionals, particularly physicians, have often not welcomed the idea of controlling medical practice and often claim that professional control undermines professional autonomy and medical expertise.[2,3] However, it remains unclear so far how physicians themselves perceive the contemporary challenges to medical autonomy and professional control.[3]

The practice of continuous deep sedation until death (CDS), might provide an interesting example in this area. CDS is a form of palliative sedation that intentionally maintains a deep state of unconsciousness until death in patients at the end of life, using sedative drugs to alleviate unbearable suffering from refractory symptoms.[4] These symptoms are extremely difficult or impossible to manage, and they can be physical or psychoexistential.[5] To take away the patient's experience of refractory symptoms, the state of unconsciousness is intended as an option of last resort.[4] More specifically, the state of unconsciousness is achieved and maintained through dose titration of the sedative drugs, for example via an infusion pump, and may last for several days as there is no intention of causing or hastening death.[6] Nationwide studies have indicated that CDS is prevalent in care settings where patients die, with prevalence estimations ranging from 3% to 19% of all deaths in Europe and 10% in the United States.[7] Additionally, several national and international guidelines about CDS have been published.[8,9] These guidelines have several conceptual similarities.[8] Similarities include that CDS should be indicated for patients close to death, with a life expectancy of two weeks or less, who suffer unbearably from refractory symptoms; that sedative drugs should be administered proportionally to the refractoriness of symptoms; and that the administration and monitoring of CDS should be performed by medical professionals, preferably physicians.[8–10] In practice, however, nurses occasionally carry out the administration and monitoring of CDS in the absence of physicians.[11,12] Moreover, most guidelines also state that physicians should conduct the decision-making of CDS based on an overall medical assessment of the patient's situation, involving patients and their families.[8] Hence, according to the strict sense of guidelines, CDS cannot be carried out without prior medical assessment.[8]

The tension between calls to reform medical practice through professional control and opposition from physicians has extended to the practice of CDS, which is seen as having potential for multiple hazards e.g.

CDS might shorten survival;[13] physicians use CDS to terminate or shorten a patient's life;[14] CDS distresses the carers and relatives involved; physicians use suboptimal drugs for the administration of CDS;[15] CDS is not carried out in accordance with guidelines e.g. using disproportionate or inadequate assessment.[16] It has therefore been suggested that CDS should be professionally regulated by control measures in order to reform and improve its practice.[17–21]

Control measures, also referred to as preventive and/or protective measures, involve non-medical interventions, actions and solutions to prevent, mitigate and eliminate the occurrence of and/or the exposure to an identified hazard.[22] Expert consultation, for example, is regarded by the European Association for Palliative Care and various guidelines as a proper control measure to prevent patients with inappropriate indications from being sedated.[6,9] Yet, there seems to be little compliance with and support for such recommendations among physicians.[19,23] Koper et al. showed that physicians show little support for mandatory expert consultation within the context of CDS for practical and theoretical reasons, holding that CDS is a normal medical practice.[19] This study also touched on another interesting element, namely the beliefs and reasoning that underlie physicians' views on control measures for CDS, an in-depth understanding of which is lacking within palliative care literature to date.[19]

With this study we aim to contribute to medical literature in general and palliative care literature in particular by exploring in depth these views and attitudes. Elaborating upon Chamberlain's recommendation that research should focus on professional control from the viewpoint of physicians themselves,[3] we argue that identifying and understanding physicians' views might provide valuable insights into better implementation of control measures for CDS practice as physicians are important actors in the medical decision-making process, and are often the only medical professionals who may indicate and administer CDS.[9] Secondly, we aim to provide information for policymakers who want to issue evidence-based and participatory control measures for CDS; the perspective of physicians should indicate which specific measures would be effective and which ones they would put into practice.

The main research question is: how do physicians frame control measures for CDS? To answer this we conducted a qualitative framing analysis on in-depth interviews with Belgian physicians, drawing upon Entman's definition of framing.[24]

CDS practice in Belgium

At present, there is a lack of recent findings on the prevalence of CDS in Belgium. Nevertheless, previous studies have estimated that CDS is carried out in 1 out of 8 deaths in Belgium, and is more prevalent in hospital settings than in home settings.[25,26] In these settings in Belgium, the care including CDS, can be provided by physicians working either individually e.g. general practitioners (GPs) in home settings, or in a team e.g. disease-specific specialists in hospital settings.

In 2012, the Federation for Palliative Care Flanders (FCPF) updated its guideline about palliative sedation including CDS.[27] This guideline states that CDS is a normal medical practice, namely a form of intensified symptom management, that can only be used to alleviate refractory symptoms in patients with a life expectancy of several days and exceptionally of more than one week.[27] To determine the refractoriness of symptoms, the guideline recommends using an interdisciplinary approach and seeking a palliative expert consultation, but puts the decision to initiate CDS under the authority of the treating physician.[27] Furthermore, it underlines that CDS differs from euthanasia, which is a legal practice in Belgium, in that it may never be intended to terminate a patient's life.[27]

Methods

Research design, sampling and data collection

We conducted an in-depth interview study with Belgian physicians using semi-structured interviews elaborating on social constructionism in order to explore the social phenomenon of the practice of CDS in all its richness.[28] This approach allows us to grasp comprehensively multiple understandings and diverse realities about how physicians define and experience the specific context of the practice and of potential control measures.[28]

Eligibility criteria for this study were: (1) being employed as a medical doctor at the moment of study inclusion, (2) residency in Belgium, (3) fluency in Dutch and/or French, (4) having given informed consent to participate in the study and, (5) having administered CDS at least three times in the last five years. Concerning the latter criterion, we reasoned that physicians experienced in or knowledgeable about initiating CDS would have more profound insight and a better understanding of the ongoing dynamics of the practice, and consequently, have more reasoned views about appropriate and feasible control measures than those who do not have experience. Participants were recruited between January and

March 2019. Purposive sampling was used to ensure sample variability in relation to our primary sampling criteria, obtaining a wide range of views and experiences: age, gender, setting, and medical specialism. This involved a multistage strategy in order to maximize validity:[29]

1. The first strategy involved a random selection of 40 hospitals across Belgium, sending a letter of invitation by e-mail with the request to physicians from oncology, palliative care, ICU, and geriatric departments to participate in the study, while clarifying the specific context, aim, and eligibility criteria. We chose these settings because the prevalence of CDS could be expected to be higher in comparison with others. Subsequently, we followed the same procedure for GPs in which we randomly selected 30 GP practices across Belgium. Interested physicians were able to register for participation on a specially designed website.
2. With regard to the second strategy, we asked several national and regional medical organizations for GPs and palliative care physicians to send out a letter of invitation to participate to its members. Interested physicians were also able to register on the website.
3. The third strategy used the snowball method. We asked participants sampled with the aid of the first two strategies to identify other potential physicians who could be eligible to participate. More specifically, participants were asked to provide the professional email addresses of these physicians. Thereafter, these potential participants were sent a letter of invitation by e-mail with the request to participate in the study. Interested physicians were also able to register on the website.

Face-to-face interviews were conducted with Dutch-speaking and French-speaking physicians. These interviews took place at the location chosen by the participants. We used a topic guide for in-depth exploration of their views on and their understanding of the reasoning behind control measures for CDS. The topic guide was structured in three themes: (1) definition of CDS and their general experience with CDS practice; (2) personal views on control measures for CDS practice; and (3) personal opinions about the implementation of mandatory registration and/or expert consultation for CDS. Significant changes were made to the third theme of the interview format after eight interviews had been conducted. Preliminary results of these interviews indicated that physicians also favoured and suggested other control measures and/or monitoring methods for CDS. Drawing upon the open-ended attitude,[30] this theme was therefore modified into 'feasible control measures, solutions, and actions for improving CDS practice'. All interviews were audio-taped and transcribed verbatim.

Ethical considerations

Ethics approval for this study (B.U.N. 143201938601) was granted from the Medical Ethics Commission of the Brussels University Hospital (2019/011). Participants provided written consent to be interviewed. Furthermore, we assigned pseudonyms to participants in the interview transcripts.

Data analysis

We conducted a qualitative framing analysis in order to map and analyze physicians' views towards control measures for CDS. Our qualitative framing analysis aimed at identifying frames inductively by constructing them from the empirical data.[31,32] Frames are organized patterns of thought schemata used by people to make sense of their social environment and to organize their experiences.[33]

The physicians' frames were identified drawing upon Entman's framework which states that frames or framing entails four interactive components, sometimes referred to as framing functions.[24] Framing is 1) defining problems, that is determining what causal agents are doing with what costs and benefits; 2) diagnosing causes, that is identifying the forces creating the problem; 3) making moral judgments, that is evaluating causal agents and their effects; and 4) suggesting remedies, that is offering and justifying treatments for the problems and predicting their likely effects.[24] The purpose of our analysis was more specifically to identify how physicians frame the problem of CDS practice and its cause, make moral and/or value judgments about this problem and/or CDS practice in general, and suggest solutions and actions, for example control measures, in order to tackle these problems and improve CDS practice.[24]

Our qualitative framing analysis entailed four phases conducted inductively in parallel,[34] Throughout all phases of the analysis, we discussed and reached consensus on outcomes from each phase. The first phase entailed an open coding system, identifying topic categories within Entman's four framing functions.[24,34,35] Initially, transcripts and interview notes were read and re-read. Line-by-line open coding was conducted by means of the qualitative data analysis software NVivo 12, organizing segments of text. The aim of this phase was to stay close to the data elaborating upon participants' words and phrases in order to provide codes.[24,34,35] Saturation was reached with regard to the collected data, since no new topic categories emerged after 80% of the transcripts had been analyzed.[24,34,35] The other 20% of the transcripts were used to verify whether the generated codes also applied to those. The second phase consisted of axial codification,[35] in which codes were reduced to a smaller number of codes converting into several topic categories for each frame function. During the third phase, the frames were created through interconnecting the topic categories with each other as a logical chain of frame functions.[24,34,35] Categories and frames were compared and discrepancies were modified until consensus was reached. Finally, the fourth phase involved the discussion and revision of the found frames in group analysis meetings.

Throughout the whole research process, we chose to structure the data collection and analysis by means of the iterative cycle of qualitative research.[36] During systematic meetings with all authors every six weeks, there was a constant reflexive process of revisiting the data connecting them with new insights with the intention of sharpening our understanding of physicians' views. Simultaneously, this reflexivity enabled us to better comprehend our own research role in order to restrain personal conceptions and ideas concerning control measures for CDS.

Results

Sample characterization

In total 53 physicians registered on the website for study participation. We screened 51 physicians eligible for participation and excluded two who had not performed at least three cases of CDS during the last five years. Of the 51 screened eligible, 49 were contacted successfully to schedule an appointment for an in-depth interview. One interview never took place, since the participant cancelled at the last-minute due to time constraints. In total 48 interviews were conducted. The in-depth interviews lasted 13 to 90 minutes (average = 44 minutes). There was an observed difference between interviews with Dutch- and French-speaking physicians in terms of length, those with French-speaking physicians on the whole being shorter with physicians having less time to be interviewed or being called away due to unforeseen medical incidents. Nevertheless, we argue that the length of these interviews did not influence the overall quality of the content. Finally, we excluded one interview from analysis because other health professionals from the palliative care team were present answering questions on behalf of the participant. In total, 47 participants were included in the analysis: 13 oncologists, 13 GPs, 12 intensive care physicians, 8 geriatricians, and 1 anaesthetist. Of these participants, 25 completed a training in palliative medicine. Table 1 provides an overview of the characteristics of participants.

Table 1. Characteristics of participants (N=47)

	N (%)
Specialty	
Oncology	13 (28)
General practice	13 (28)
Intensive care medicine	12 (26)
Geriatrics	8 (17)
Anaesthetics	1 (2)
Additional training in palliative medicine	25 (53)
Care setting	
Hospital	34 (72)
Home	13 (28)
Age (years), mean	46
Younger than 35	7 (15)
35-44	8 (17)
45-54	15 (32)
55-64	12 (26)
Older than 64	5 (11)
Gender	
Male	26 (55)
Female	21 (45)
Number of treated patients who died in previous 12 months	
none	0 (0)
1-5 patients	2 (4)
6-10 patients	7 (15)
> 10 patients	38 (81)
Number of patients for whom CDS was performed in previous 12 months	
None	0 (0)
1-5 patients	14 (30)
6-10 patients	5 (11)
> 10 patients	28 (59)

Throughout the interviews, it is apparent that most participants emphasize two aspects repeatedly in an explicit or implicit way, namely, 1) that they are competent in administering CDS and, 2) it is ‘time to act’ to improve CDS practice. Regarding the first, all participants identify themselves as being qualified for performing CDS. Most of them link this competence to their frequent experience with CDS practice itself, ‘palliative culture’ as a whole, and/or thorough knowledge of guidelines about palliative sedation and CDS. In addition, all participants assert that they only administer CDS with good intentions, acting in the best interests of patients and/or their relatives. Most participants say that providing the best possible medical care for patients and/or relatives is their underlying ‘main motive’ for carrying out CDS. Participants moreover describe the administration of CDS as fulfilling their ‘medical moral duty’ towards patients and/or relatives, since they consider that no other medical treatment can be performed as an adequate response to the patient’s refractory symptoms. Also, they believe that the majority of physicians who administer CDS share the same intentions. Apart from these intentions, most however argue that CDS is in general practiced sub-optimally and some even speak of ‘malpractice’. Malpractice in this particular context refers to the intentional use of CDS by physicians to terminate or shorten a patient’s life; all participants were united to a certain degree by the conviction that it is ‘time to act’ in order to improve CDS practice as a whole. Implementing actions and/or solutions is perceived as a necessary vehicle for improvement, since these problems do not tend to resolve themselves.

Frames that construe participants’ views towards control measures for CDS

Despite overall agreement among participants that certain action is needed, their views differ with regard to the types of problems arising within CDS practice, the reasons and causes underlying these problems, and the possible solutions and actions, i.e. control measures and monitoring methods, for addressing them. Different explanatory models and reasoning are thus employed in order to give meaning to these control measures for CDS, i.e. frames. We identified five frames among participants: ‘control through expertise’ frame, ‘strict due care’ frame, ‘safeguarding patient choice’ frame, ‘facilitating dignity’ frame, and ‘improving communication’ frame. It is important to note that we as researchers have given these names to the frames based on our interpretation of the most salient features of participants’ views.

In the following sections, we present the five different frames in more detail and describe the inherent four frame functions of each frame: 1) defining the problem(s), 2) the underlying reasons for or causes of these problems, 3) inherent value judgements, and 4) possible solutions and actions (control measures) in order to tackle them.24 Table 2 shows a summary of each frame and its frame functions. Although we describe each frame separately for analytical reasons, participants use various frames and frame functions simultaneously.

Table 2. Five frames that construe participants' views on control measures for CDS

	Problem definition	Problem source	Value judgment	Solutions and actions
Control through expertise	Physicians lack knowledge and experience to perform CDS	CDS is a complex and specialized practice	CDS is a normal medical practice that should be performed by experts	Expert consultation; training and education
Strict due care	Physicians employ CDS with the wrong intention	Physicians' paternalistic attitudes	CDS can only be used for relieving intolerable suffering from refractory symptoms	Registration of CDS; shared decision-making
Safeguarding patient choice	Patients wish to die in their sleep	Seeking a good death	Self-determination and patient autonomy/choice are inviolable	The legal option of initiating CDS to accompany the dying process of patients
Facilitating dignity	Some patients with severe loss of mental capacity die in a context lack of dignity, according to their relatives	The lack of legal framework that facilitates all end-of-life decisions	Every human being deserves a dignified death	Legal protection of physicians who initiate CDS to facilitate a dignified process of dying for patients with a severe loss of mental capacity
Improving communication	Patients' relatives have misconceptions about CDS	A lack of physician communication	Information sharing is key	Refining and improving the communication skills of physicians; raising public awareness

Control through expertise frame

According to the control through expertise frame, the problem of CDS practice stems from participants' belief that other physicians lack the knowledge and experience to perform CDS well as they only do it rarely. This belief is grounded in the participants' experience that the majority of their fellow physicians who carry out CDS make multiple errors in terms of both indications i.e. whether or not symptoms are actually refractory, and technique, i.e. not utilizing the recommended drugs or appropriate dosage. In this regard, participants particularly incidence GPs and physicians of an older generation who do not have the right competences for initiating CDS.

Participants who use this frame locate the source of the problem in the nature of CDS, which is considered to be a complex practice which requires specialized skills due mainly to its unforeseen side-effects, for example, sedated patients may awaken at any time during the sedation or die unexpectedly. Furthermore, it is particularly difficult to determine and adjust the accurate doses and type of medication necessary and sufficient to maintain the patient in a tranquil and tolerable condition because every patient responds differently. Secondly, participants claim that education and training programs for physicians have not paid comprehensive attention to palliative care, end-of-life practices and CDS practice in particular, which has led to significant ignorance about CDS among physicians.

The inherent value judgement in this frame focuses on the assumption that CDS is an exceptional but normal medical practice that should be performed by physicians with full knowledge of the criteria for CDS. Some participants further posit that CDS should be embedded only in secondary or tertiary care services highlighting both the suboptimal practice occurring in primary care and the specialized character of the practice.

"Physicians do not have the skills, which are very important in order to initiate CDS correctly. Also, the chance of success might be higher. Initiating sedation is always difficult, because one never knows what will happen. Even if one has chosen the proper moment, it might turn out differently."

-Participant 12, oncologist-

This frame encompasses two solutions which are grounded in mechanisms that concentrate on acquiring the proper competences to perform CDS. The first stresses the importance of consulting an expert before the administration of CDS. Expert consultation is more specifically described as a reciprocal communication process between the treating physicians and an expert specialized in CDS practice, preferably from secondary or tertiary care services, preceding the initiation of CDS, that focuses on addressing issues with regard to CDS, preventing and resolving situations rapidly to minimize risks and creating better patient outcomes. The underlying idea is the principle of 'teach one, learn one' so that physicians' misconceptions and concerns about indication and performance of CDS could lead to good clinical practice due to the expert's guidance and input during the consultation. The second solution is education and training which targets a physician's knowledge and skills about CDS; intervision sessions among peers, peer coaching and bedside teaching are seen as effective training methods to reinforce and strengthen competences. In addition, most participants using this frame criticize heavily the use of registration as a possible solution, referring to the 'ineffective' registration procedure in euthanasia practice. The latter is merely perceived as a 'list of check boxes' without any educational effect and thus as not doing anything to improve the competence of the physician.

Strict due care frame

This stems from the perception that physicians do not use CDS solely with the intention of reducing the patient's level of consciousness in response to unbearable suffering from refractory symptoms. The perception is that, firstly, the majority of physicians use CDS with the intention of providing comfort and/or relieving pain from non-refractory symptoms while there is still scope for other treatments and interventions to reduce the pain and secondly that some initiate CDS with the intention of shortening or terminating a patient's life, sometimes without the consent of the patient.

According to this frame, this is because some physicians are not inclined to question their own intentions and exhibit a lack of self-reflection while identifying strongly with a paternalistic professional identity, leading them to the belief that they are best-positioned to decide, and act on, what is in the best interests of the patient. Their opinions are thus impossible to argue with and the patient and/or their relatives have to comply silently. This, according to some participants, is the consequence of the societal prestige and status inherent to the profession of medicine.

The value judgement underlying this frame is that CDS can only be used to mitigate intolerable suffering from refractory symptoms that cannot be alleviated otherwise. Participants strongly condemn the practice of administering it for other reasons and emphasize that CDS and euthanasia are two distinctive end-of-life practices with different intentions. If a patient clearly requests medical aid to end his or her life, it is the physician's role to explore with them the option of euthanasia which is legal in Belgium but CDS should only be performed in strict accordance with the indications.

The main solution in this frame involves challenging a physician's intentions by breaking down their paternalistic attitudes; two solutions are suggested. One involves implementing mandatory registration of CDS involving filling in a registration document in which intention of administering CDS must be indicated, which would require self-reflection leading to awareness of underlying intentions and have a deterrent effect on the use of CDS to shorten a patient's life, as all registered information could be checked. The other is a mandatory requirement for shared decision-making among multiple professionals which could counter any unilateral paternalistic intentions on the part of the physician.

"Physicians are messing around with sedations without paying attention to indications. They try to avert euthanasia through CDS. […] Like the old model, physicians decide everything and nurses have to comply with it. As a palliative care team, we have stepped in to stop this practice. We felt that we had to take up our role, because we as doctors have more influence on our colleagues."

-Participant 23, oncologist-

Safeguarding patient choice frame

In this frame the problem is that many patients express the wish to die in their sleep or to be unconscious during the process of dying, thus explicitly demanding CDS. Some participants explain that these requests mainly come from religious patients who are strongly opposed to euthanasia. This leads to a certain moral tension between meeting the patient's wish and the principle of fulfilling all the required indications for CDS. Regardless of this dilemma, participants declare that they prefer meeting the patient's wish, and thus performing CDS to accompany the process of dying on the condition that the majority of indications are met, namely (1) the presence of severe physical symptoms, (2) unbearable suffering, and (3) nearing death.

"Sedation is a choice that patients can make. We have had a few cases where people say they wanted to sleep. They do not want to experience it anymore. We explain that this is only possible with a life expectancy of two weeks. […] I really see it (CDS) as a stopgap solution, especially when people are not open to euthanasia."

-Participant 11, general practitioner-

According to participants using this frame, the source of the problem is based on patients seeking a ‘good’ or ‘peaceful’ death. Patients mainly identify a good death with a painless death or a minimum of suffering at the end of life and have a strong fear of suffering which causes even more distress. This frame furthermore argues that this anxiety is partially the consequence of a public stigma and taboo surrounding death and the fear that they might not be able to cope with the dying process.

Participants using this frame highly value both self-determination and patient autonomy; the patient’s choice is given priority over the principle of meeting all indications for CDS. According to these participants, patients have the right to ‘orchestrate’ or determine the dying process on their terms, not those of the treating physician. In other words, one must respect the patient’s choice, even if this entails terminating or shortening life by means of CDS. This belief is partially enhanced by the view that it is a physician’s moral obligation to cover a patient’s needs in terms of being responsive to and respectful of their preferences and wishes regarding care.

The solution focuses on drafting legislation establishing the right to perform CDS at the request of patients who are nearing death. As such, many of the physicians in this frame praise the spirit of the enacted Claeys-Leonetti law in France which provides a legal framework for CDS.

Facilitating dignity frame

The problem in this frame is associated with the fact that participants regularly experience pressure from relatives to shorten or terminate a patient’s life by means of CDS. Relatives request this for patients with a major or total loss of mental capacity, primarily those with advanced dementia or a minimally consciousness state due to irreversible brain damage in ICUs. These relatives see themselves as the patient’s ‘spokesperson’ since the patient can no longer speak for him or herself. Their role involves advocating for the patient’s care and end-of-life preferences, emphasizing the patient should die in dignity.

"And the family are asking me: ’So Doctor? And now? What are you going to do now? He is lying there. You are going to give him something, right? You are going to do something, aren't you?'. These people are furious. Furious! And then 'the dog', the story of the dog. Over and over again. […] So ultimately, I administer CDS ."

-Respondent 42, intensive care specialist-

The frame attributes the problem to the fact that relatives and/or the patient's legal representative are hardly heard when it comes to end-of-life care and/or medical end-of-life decisions, and the lack of a comprehensive legal framework regarding all end-of-life decisions for patients, especially for those with a major or total loss of mental capacity. Participants say they often feel frustrated about this legislative 'gap' that needs to be tackled with 'great urgency'.

The value judgment in this frame is that CDS may be initiated as a means to shorten or terminate the life of someone with severe loss of mental capacity at the explicit request of relatives. In fact, these participants declare that they or colleagues have already executed CDS with this intention. They view the medical practice of CDS not as an end in itself but rather as a means to facilitate a death in 'human dignity', a dignified dying process. This is partially embedded in the view that they cannot imagine experiencing their own end-of-life in the same 'inhumane' circumstances.

As a solution, participants suggest legal protection for physicians who deploy CDS in order to facilitate a dignified death for patients with severe loss of capacity at the request of the patient's relatives.

Improving communication frame

Participants believe that physicians perform CDS particularly well, especially in technical terms, though there is a 'rather minor' problem in that, according to them, relatives do not always have a clear idea of what CDS exactly entails and hold multiple misconceptions and beliefs about it, for example that it shortens the patient's life. Therefore, most relatives are relatively upset when they have to wait too long for death to come after the initiation of sedation which often leads to incomprehension and frustration which can escalate into a conflict between the treating physician and the relatives.

Participants note that the problem of misunderstanding about CDS is the result of a lack of appropriate communication between the physician and the relatives. Whereas physicians have the skills in diagnosing and treating a patient, they can be less than 'tactful' in their communication. Also, they have less time to explain fully all the specific details and consequences of their medical actions to their patients, due to work overload. Participants explain that this is particularly grounded in an education that had not paid sufficient attention to the development of soft skills, but was solely focused on clinical skills. Nevertheless, they believe that physicians from a 'younger generation' have fewer difficulties with communication skills.

These participants say they greatly value 'communication' and 'information sharing'. This is described as the process by which someone explains in a clear, concise and well-organized way their medical actions and decisions and the consequences and risks to the patient and their relatives. In the case of CDS, they see this as providing all background information in terms of intention and potentially unforeseen outcomes, such as sudden death, awakening during sedation, and the unpredictability of the time of death.

“When we initiate CDS, the family knows what our palliative treatments are. We are very clear on that. We give all the information, so the patient knows from the very beginning what CDS and euthanasia include. [..] That is the package we offer.”

-Participant 39, geriatrician-

The frame encompasses two solutions. One is training in good communication skills, for example during peer intervision; they consider current training should pay more attention to physician-patient communication. Another is a public awareness-raising campaign addressed directly to the general public, for example distributing information brochures across all general practices, describing in detail all medical end-of-life decisions in ‘plain language’ with a particular focus on CDS.

Discussion

Summary of main findings

Participants make sense of control measures for CDS by using five different frames. The ‘control through expertise‘ frame suggests that control measures should focus on providing the proper expertise to physicians who carry out CDS, since CDS is a normal, if exceptional, medical practice that requires unique competences. The ‘strict due care’ frame postulates that control measures should change physicians’ paternalistic attitudes, which often lead to unilateral medical decision-making in which the initiation of CDS is discordant with the recommended due care criteria. The ‘safeguarding patient choice’ frame posits that control measures for CDS should establish the right to perform CDS at a patient’s request because many patients wish to die in their sleep, even when not all criteria for CDS are met. The ‘facilitating dignity’ frame stresses that control measures should legally protect physicians who perform CDS in order to facilitate a dignified death for patients with a severe loss of mental capacity. The ‘improving communication’ frame emphasizes that control measures should enhance the communication skills of physicians, since the relatives of sedated patients are not fully informed about the consequences of sedation.

Strengths and limitations

To the best of our knowledge, this is one of the first studies to provide qualitative in-depth accounts of how physicians frame control measures for CDS. We have sought to expand current knowledge by concentrating on multiple control measures suggested by physicians themselves. The main strength of this study concerns deploying a framing analysis based on Entman's notion of framing in order to explore how physicians make sense of control measures for CDS by identifying specific frames.[24] Our methodological approach of analytically assessing single frame elements tends to have a higher reliability and validity,[37] reducing researchers' bias in the data analysis process,[38] and enhancing transparency and trustworthiness,[39] than does the approach of identifying holistic frames without framing functions. This framing analysis allowed us to elucidate latent and layered meanings behind the words and narratives offered by physicians commenting on the social phenomenon of control measures for CDS. A simple thematic analysis would have merely provided a description of problems and solutions.[40]

With regard to limitations, the interviews were carried out at a time when public debate in Belgium was questioning whether stringent control measures for CDS should be implemented by public authorities. It is therefore possible that this focus has convinced certain physicians to participate in this study, for example those who firmly support or oppose such implementation or those who are very confident of their own CDS practice. We sought to reduce bias of this sort by incorporating a wide range of participants with a variety of different views and experiences in order to strive for a maximal theoretical generalizability of the findings. In addition, our findings might not necessarily be theoretically generalizable to contexts outside Belgium. Participants are rooted in Belgian society, a sociocultural context in which physicians generally hold relatively permissive attitudes towards end-of-life decisions and actual end-of-life decision-making, and apply a broader conceptualization of CDS in practice than in other countries.[41,42] Therefore, it should be remembered that different frames may exist in other countries or contexts.

Interpretation of the findings

This study contributes to literature in multiple ways: it expands the general finding that different physicians perceive the practice of CDS - and inherent control measures - quite differently; it provides nuance about the common premise that physicians prefer the idea of professional self-regulation in medical practice and it illustrates that physicians consider it important that several aspects of end-of-life decision-making should be safeguarded.

Palliative care research has paid much attention to the question of how physicians and health professionals as a whole approach CDS practice; health professionals and physicians may differ in terms of attitudes, perceptions, experiences and reasoning towards it.[43–46] Our findings expand on this by suggesting the existence of various frames among physicians. Participants in our study take different stances in terms of problems and their causes that arise in CDS practice, and the value judgements related to them. Our findings not only demonstrate there is interpersonal variation between participants as regards framing of control measures for CDS, but also intrapersonal variation. Participants often switch from one frame to another, employing up to three frames, sometimes being conscious of probable contradictions. Throughout their narratives, the 'control through expertise' frame is used interchangeably with the 'improving communication' frame, while the 'safeguarding patient choice' frame especially interacts with the 'facilitating dignity' frame. Although the 'strict due care' frame shows fewer defined patterns of intertwining with other frames, participants who adopt this frame occasionally use arguments from both the 'control through expertise' and 'safeguarding patient choice' frames. These combinations of frames indicate that certain frames are more compatible to each other than to others. This might explain why the public debate in Belgium about implementing stringent control measures for CDS, in which important stakeholders such as the Chairs of the Belgian Federal Control Commission for Euthanasia and the Federation of Palliative Care Flanders take opposite positions, has been considerably polarized. Therefore, our frame analysis might help these stakeholders to find common ground.

Our findings put into doubt the premise common in the vast literature on the subject that physicians are more inclined to favour the idea of professional self-regulation or self-governance rather than state governance or even 'interference'.[3] The frames point in different directions when it comes to determining who should issue control measures for CDS. The 'facilitating dignity', 'safeguarding patient choice', and 'control through expertise' frames point in the direction of government interference, for example in the form of registration of CDS cases performed, or of developing a legal framework for CDS. Viewpoints within these frames might be attributed to a spillover effect of participants' positive attitudes towards the control measures for the practice of euthanasia, which are regulated in Belgium by means of a legal framework of mandatory registration.[42,47] This may also explain why these frames often include concepts used in discussion of euthanasia practice, such as dignity, patient choice and self-determination.[48] The 'control through expertise' and 'the improving communication' frames, however, show preference for professional self-regulation over external control for example in the form of expert consultation or training. This seems to stem from participants' perception that CDS is a normal medical practice,[19] as explicitly indicated within the ‘control through expertise’ frame. Another plausible explanation may be that these participants view professional self-regulation as a supportive measure giving them more confidence in terms of sound medical decision-making.[49]

Our findings show that participants believe that a range of issues should be focused on when safeguarding end-of-life care and decision-making. The ‘control through expertise’ and ‘improving communication’ frames highlight control measures that improve physicians’ expertise and communication. These views might be driven by a rather paternalistic model of medical decision-making or of CDS practice in particular as central to the model is a basically one-way flow of information from the physician to the patient with a minimum of participation from the latter, with medical deliberations and decisions made by the treating physician alone or in consultation with other physicians.[50] Physicians appear to adopt such attitudes towards medical decision-making in order to preserve their professional authority and autonomy,[51] and although recent models of decision-making consider them undesirable, some authors suggest ‘palliative paternalism’ is the right way to make difficult medical decisions at the end of life.[52] However, participants using these frames seem to be rather more ‘modern’ than ‘classical’ paternalists. They tend to decide for the patient, but simultaneously underline the importance of knowledge of and understanding by the patient, persuading him/her that the medical decision to initiate CDS is right.[53] Analogously, the ‘facilitating dignity’ and ‘safeguarding patient choice’ frames seem to safeguard the decisions and values of patients and relatives and those deploying these frames appear to be driven by models of shared decision-making. Compared with the paternalistic model, these models take the values, preferences, and needs of the patient into consideration more and make room for more patient participation in the decision-making process.[54] This could be viewed as the manifestation of a more patient-centered orientation on health care.[55] Lastly, the ‘strict due care’ frame insists that all clinical indications should be met in order to initiate CDS, particularly stressing refractory symptoms and intolerable suffering. These participants privilege strict compliance with CDS guidelines which may indicate that they have strongly internalized them. A plausible explanation for this might be that more attention has been given in the last decade to the development and use of such guidelines for CDS in order to steer medical practice.[9]

Recommendations and implications

Answering the question of whether policymakers should implement control measures for CDS is beyond the scope of this study. Nonetheless, we do argue that a key question for policymakers is how to hold physicians accountable for achieving good-quality care in cases of CDS. In this respect, our findings indicate that policymakers who seek to implement control measures should first clarify the core issues they want to tackle in light of the ethical and public debate. This study may help them in deciding which measures are necessary, feasible and effective. Our findings could contribute to such evidence-informed policy-making by establishing physicians' frames and patterns of reasoning through linking problem definitions with measures to counter them. Moreover, the identified frames may support policymakers in predicting the effectiveness of certain control measures within the medical field, since frames are not merely cognitive structures but also represent cultural elements.[56] Control measures that do not align to a certain extent with physicians' frames seem highly unlikely to be adopted and applied by physicians. Moreover, policymakers should also consider the effect of implementing control measures on the public and on medical framing of CDS practice itself and to what extent this is desirable. In this respect, it seems not unlikely that if CDS practice becomes subject to a post-hoc review, medical professionals might have difficulty in distinguishing it from euthanasia.[17]

A future research direction might explore how the implementation of control measures might impact the practice of CDS. Also, participants in our study have suggested that control measures could take various forms, governed by different organizational structures. Therefore, future research may examine whether either the state or the medical field would be the most efficient and effective structure in which to monitor these control measures.

Although most national and international guidelines and medical decision-making models for CDS and palliative sedation have solely incorporated the recommendation of deploying expert consultation as a proper control measure,[9,10] our participants suggest that they could be expanded with other control measures in order to improve CDS practice significantly. Furthermore, it seems important that education and training programmes for physicians should not solely focus on clinical technicalities and indications when it comes to the initiation of CDS, but should pay equal attention to the surrounding decision-making and communication processes involving all actors concerned.

References of Chapter 6

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Chapter 7

Experiences and perceptions of environmental factors affecting their practices of continuous deep sedation until death: a secondary qualitative analysis of an interview study

Stijn Vissers, Sigrid Dierickx, Lenzo Robijn, Joachim Cohen, Luc Deliens, Freddy Mortier, Kenneth Chambaere

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Abstract

As previous research has paid little attention to environmental factors affecting the practice of continuous deep sedation until death (CDS), we aimed to explore these using physicians' experiences and perceptions. We performed an interpretative thematic analysis of primary data from a qualitative interview study conducted from February to May 2019 in Belgium with 47 physicians. Structural factors were identified: the lack of professional and/or technical support in monitoring sedated patients; the use of guidelines in team contexts; the time constraints for treating individual patients and work pressure; the structural knowledge gap in medical education; the legal context for assisted dying, and the lack of a clear legal context for CDS. Cultural factors were identified: the moral reservations of care teams and/or institutions towards CDS; the presence of a palliative care culture within care teams and institutions; the culture of fear of making clinical errors regarding CDS among a group of physicians; the professional stigma of performing assisted dying among some of the physician population; the different understandings of CDS in the medical and policy fields; the societal taboo around suffering at the end of life and natural death. To conclude, improving CDS practice requires a whole-system approach considering environmental factors.

Introduction

At the end of life, some patients might experience unbearable suffering from refractory symptoms that are extremely difficult or impossible to manage.[1] For these patients, continuous deep sedation until death (CDS) can be performed as an option of last resort to mitigate the suffering.[2,3] This involves the intentional lowering of patients' consciousness in a deep and prolonged state until death, so that patients are no longer aware of their unbearable suffering.[2]

While studies have shown that the prevalence of CDS is considerable,[4] they have simultaneously established that it varies between countries.[5] A comparative cross-country study, for instance, found that prevalence differs between European countries, ranging from 2.1% of all deaths in Denmark to 8.5% in Italy.[6] It is notable that the authors of the study partially attributed the higher prevalence in Italy and Belgium to the countries' overarching cultural-religious context. This reflects the claim of Anquinet et al., who connected the differences found in the prevalence of CDS between Belgium, the Netherlands, and the United Kingdom in part to the legal, cultural, and organizational factors of these countries.[7] Secondly, the prevalence of CDS also varies substantially between care settings. In this respect, a systematic review demonstrated that the prevalence of CDS differs between hospitals, hospital departments, (palliative) care units, nursing homes, hospices, and home settings.[5]

The practices of making decisions about and performing CDS, hereafter referred to as (CDS) practice, have also been found to differ between countries.[5] The international UNBIASED, for example, illustrates that rapid induction of CDS is more common in the Netherlands and Belgium, while proportional induction of CDS is the norm in the United Kingdom.[8–11] The authors of the study concluded that CDS encompasses a spectrum of practices that are partly embedded in national cultures, such as the legal and ethical context. Simultaneously, variations in CDS practice between care settings have been identified. Arevalo et al., for example, has demonstrated that Dutch physicians were less often present at the start of CDS in nursing homes/hospices and hospitals than in CDS at home.[12]

To understand the variation in CDS, literature has particularly focused on the underlying factors affecting its practice. In that regard, clinical and (inter)personal factors have been extensively examined in particular.[13] (Inter)personal factors are non-clinical influences within the micro context related to individuals and their interactions.[14] Among the clinical factors, studies show an increased probability of receiving CDS in patients with cancer, dyspnea , and psycho-existential suffering.[13,15–17] Among the inter(personal) factors, studies demonstrate an increased probability of receiving CDS in male patients, younger patients, and patients treated by deeply secular physicians and by physicians in favor of assisted dying.[5,18]

While several authors have explicitly suggested that the environmental context might play a role in the variation of CDS,[5–8,11,12] studies have rarely examined the environmental factors affecting CDS practice. These factors, also called the 'environmental context', are influences within the meso and macro context that are external to individuals.[14] Insights into the environmental factors might aid in addressing challenges that affect optimal practice of CDS. For example, some practitioners deploy CDS to hasten death in order to mitigate proxies' burden,[19] suboptimal medication is sometimes used to initiate CDS,[20] proxies are often not involved in the decision-making about CDS and they may put practitioners under pressure to induce CDS,[9,21] and practitioners may experience emotional and moral distress throughout CDS practice.[9] Moreover, few quality improvement initiatives have been successful in addressing these challenges in practice,[22] which may indicate a poor understanding and underestimation of the importance of the broader context.

This article aims to explore physicians' experiences and perceptions of the environmental factors affecting their CDS practices. The main research question of this study is: What are physicians' experiences and perceptions of what environmental factors affect their practices of CDS? To that end, we conducted a secondary analysis on primary data from a qualitative interview study with Belgian physicians.[23] The particular focus on perceptions and experiences of physicians has been chosen because they are prominent protagonists in CDS practice. Moreover, they are often the only medical professionals who are legally authorized to perform CDS in most jurisdictions.[24]

Methods

Study design

We performed a secondary study drawing on primary pre-existing data, namely in-depth interviews with physicians, from a broader qualitative primary study that explored physicians' framing of CDS practice and its appropriate control measures.[23] Findings on the latter are reported elsewhere.[23] Following Heaton's classification of secondary studies, our study design reflects an inside supplementary approach.[25,26] This involves the in-depth examination of an issue or aspect of the primary data by the same researchers that was not addressed or was only partly covered in the primary study.[26,27] Moreover, the emphasis might be on a particular issue or theme that emerged in the primary study.[26,28] In the first study, a subsidiary finding was that physicians in our sample pointed out to several environmental factors impacting their CDS practices, especially when prompted to discuss the context in which their own CDS practices are embedded. Consequently, we decided to conduct a secondary study to explore these environmental factors in depth, thereby addressing the knowledge gap on this topic. Furthermore, performing a secondary study is deemed appropriate when the research aim is closely linked to the one of the primary study.[29–31] By conducting a secondary study, on the one hand, we endorse the methodological argument that re-analyzing primary data maximizes their fullest use.[26] On the other hand, we argue that this is particularly relevant as physicians are considered to be a challenging population to be recruited for qualitative research.[30]

The Consolidated Criteria for Reporting Qualitative Research (COREQ) guidelines were followed to ensure rigor in the reporting of this article.[32] We will discuss the methods of our primary and secondary studies in detail in the following sections.

Study context

With regard to the study setting, we conducted the primary study in Belgium among physicians with experience in performing CDS. CDS is estimated to be performed prior to one of eight deaths in Belgium, and to be more prevalent in hospital settings than in home settings.[33,34] Moreover, CDS practice in Belgium is currently not regulated by a specific legal framework stipulating its legal requirements.[24] However, the common legal perspective in Belgium involves that CDS is a form of symptom control, thus being a 'normal medical practice' that physicians are legally allowed to employ.[35] This is also emphasized by various organizations and associations, for example, in the assisted dying reports of the Belgian Federal Control Commission for Euthanasia,[36] in the guidelines for palliative sedation of The Federation of Palliative Care Flanders,[37] in ethical advice on palliative sedation of the Flemish network of care organizations Zorgnet-Icuro,[38] or in the support guidelines for physicians of the Life End Information Forum.[39]

Primary study: research paradigm

The research paradigm of our primary study, i.e., set of beliefs and assumptions that guide the research process,[40] was based on social constructionism.[41] As such, we sought to grasp the social phenomenon of CDS practice, namely, the multiple understandings and diverse realities of how physicians define and experience the specific context of the practice and potential control measures.[23]

Primary study: participants and recruitment

Physicians with experience in performing CDS were recruited. More specifically, eligibility criteria were: (a) having carried out CDS at least three times in the five years prior to the interview, including once during the past year; (b) residency in Belgium; (c) fluency in French and/or Dutch; (d) having given informed consent to participate in the study. Recruitment took place from January to March 2019 in Belgium.

To cover diverse experiences, both purposive and snowball sampling were deployed during participant recruitment using a multistage strategy to maximize validity.[42] With regard to purposive sampling, an invitation letter explaining the eligibility criteria and study purpose was sent to a) 40 hospitals (four hospitals in each Belgian province) and 30 general practices (3 practices in each Belgian province), both identified through the website of the Belgian National Institute for Health and Disability Insurance; and to b) national and regional physician and palliative care organizations. With regard to snowball sampling, participants were asked to identify other potential participants. We aimed to include a wide variety of participants in terms of age, sex and regional location of professional practice.

Primary study: data collection

Authors S.V. and L.R. and a data manager conducted the interviews in the primary study between February and May 2019. Both authors have a background in health sociology and the data manager has a background in nursing. All interviewers were familiar with interviewing on health-related or end-of-life care topics. We used a semi-structured interview guide containing open-ended questions about physicians' experiences with CDS practice. More specifically, questions were centered around three main themes: (a) personal practices of CDS, (b) feasible control measures for CDS, (c) solutions and actions for improving CDS practice. The topic guide was developed by authors L.R. and K.C. who have profound expertise in the literature on CDS and in conducting in-depth interviews. All interviews were conducted face-to-face and were held at the location chosen by the participants, which was always their professional practice. Interviews were audio-recorded using digital voice recording devices. A professional transcription service transcribed the interviews verbatim.

Primary study: ethical considerations

The Medical Ethics Committee of the Brussels University Hospital (2019/011) approved the primary study (B.U.N. 143201938601; January 23, 2019).

We assigned pseudonyms to all respondents in the transcripts and removed any identifying information. All physicians provided written informed consent to participate in the study.

Secondary study: secondary qualitative analysis

We performed a secondary qualitative analysis on the data from our primary study.[23,25–27] Given the research question of the secondary study, the overall process of our secondary analysis was informed by the theoretical framework of new ecology of social practice, which merges the ecological and constructivist traditions.[43,44] This implies that we considered CDS practice as a social practice consisting of interconnected and dynamic ecological systems or levels, namely, micro, meso and macro levels.[43–46] Moreover, following the constructivist thinking within new ecology of social practice, we aimed at capturing the environmental context as the whole of multiple, subjective realities or factors rather than as one single, objective reality.[43,44] More specifically, our purpose was to identify these factors and situate them within ecological levels instead of merging them in one interplay in order to obtain 'one environmental context' of CDS practice. To that end, we considered the individual experiences and perceptions of physicians as the unit of analysis, which is in line with the primary data.

All the in-depth interviews conducted for the primary study were included in the secondary qualitative analysis. This resulted in the analysis of the experiences and perceptions of 47 physicians. Full transcripts of the in-depth interviews were analyzed, namely, physicians' answers to all the questions in the topic guide. To increase the rigor, we used uncoded transcripts for the secondary analysis to minimize the influence of the primary analysis.[27]

The secondary analysis drew upon an interpretative thematic approach using inductive and deductive coding and theme development throughout different phases iteratively.[30,47,48] This approach is characterized by applying systematic procedures for identifying themes in the data that are common, dominant, or significant.[30] NVivo 12 software was used to organize the transcripts into structured codes and themes.

The first phase of the secondary analysis included open coding and categorization of the raw data.[30] The purpose was to identify all factors and influences impacting physicians' practices of CDS in the raw data. To begin with, authors S.V. and S.D. independently analyzed a first set of 12 interviews to identify codes in relation to such factors and influences considering the inherent meanings in the transcripts. Codes were created by attributing meaning to text fragments. S.V. and S.D. developed their own coding frames based on the coding of the 12 interviews. Thereafter, both coding frames were compared with each other. Differences and inconsistencies were discussed until consensus on one preliminary coding frame was reached. S.V. employed the merged coding frame to code the other transcripts. The coding frame was modified when new codes emerged by means of constant comparison. After the coding of all transcripts, S.V. and S.D. critically evaluated all codes. Consequently, some codes were grouped together, resulting in 42 codes.

The second phase involved the development of themes related to the context of CDS practice.[30] To that end, S.V. and S.D. merged the 42 codes in broader categories based on their similarities and relationships in an iterative and consensus-based process. In total, 22 themes were identified. Following the theoretical framework of new ecology of social practice, they situated the identified themes onto one of the three ecological levels: micro, meso, and macro.[43,44] Micro was approached as the context of influence that originates from individuals and their interactions.[49] Meso was approached as the context of influence that is embedded in medium-level systems: institutions, organizations, settings, groups of individuals and populations, communities, etc.[49] Macro was approached as the context of influence that is embedded in large systems: society, public policies, government, legislation, economy, societal fields e.g. medical or educational field, etc.[49] This resulted in an initial framework of contextual factors impacting CDS practice.

The third phase included generating a final framework that encompassed the phenomenon being studied, i.e. the environmental context of CDS practice, in an iterative and consensus-based process, including four group meetings with all co-authors. Firstly, we discussed the initial framework of contextual factors impacting CDS practice. We reassessed the meanings of all identified themes and to what extent they differed from each other. Secondly, we also reassessed whether they really belonged to the micro, meso, or macro level. After this ‘horizontal assessment’, we considered whether certain patterns were apparent ‘vertically’ across the themes. With regard to the meso and macro levels, i.e. environmental context, we deemed that the identified themes could be clustered together around culture and structure. In this way, we also adhere to new ecology of social practice in that research should pay attention to the notion of culture and structure as both might steer the behaviour and social agency in individuals.[43,44] In accordance to this framework, we consider culture and structure as reciprocal spheres of influences.[43] In other words, structural factors are assumed to impact cultural factors and vice versa. The third phase resulted in a final framework of twelve environmental factors impacting physicians’ practices of CDS. Below, we discuss the content of these factors in detail.

Results

Participant characteristics

Forty-seven physicians were included in the secondary analysis (Table 1). The mean length of the in-depth interviews was 44 minutes. Participants had a professional background in oncology, general practice, intensive care medicine, geriatrics, and anesthetics. More than half of the participants had completed additional training in palliative medicine. Most participants were medical specialists in the hospital setting. The average age of participants was 46 years and the majority were male. Seven out of ten participants had performed CDS at least 6 times in the 12 months prior to the interview.

Environmental factors

An overview of the environmental factors identified by our analysis can be found in Figure 1. They were categorized into culture and structure as we believed that these overarching categories most accurately resonated with them. We defined structure as the entirety of systematically organized objects, parts, and elements. Culture, on the contrary, was defined as the entirety of shared views, attitudes, perceptions, norms, opinions, customs, and values.

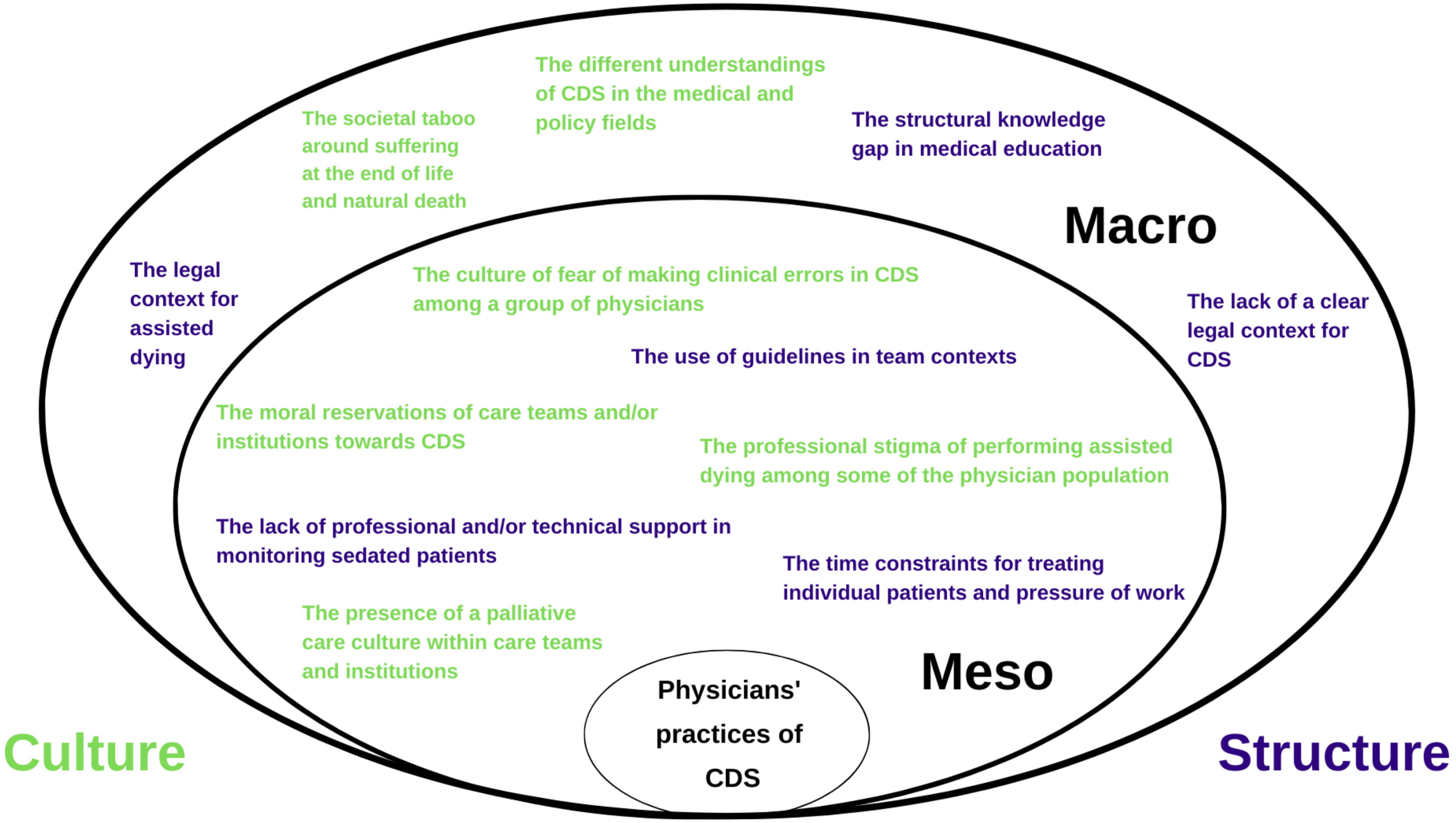
All environmental factors are presented in this article as distinctive features for analytical clarity. However, it should be noted that in reality the factors are often intertwined. In the following sections, we describe the environmental factors in detail using participants' spoken words (speech marks) and verbatim quotations (italics) to add depth and richness to the reporting of our findings.[50]

Table 1. Characteristics of the 47 participants

	N (%)
Medical specialty	
Oncology	13 (28)
General practice	13 (28)
Intensive care medicine	12 (26)
Geriatrics	8 (17)
Anaestetics	1 (2)
Additional medical training in palliative medicine*	25 (53)
Care setting	
Hospital	29 (62)
Home	18 (38)
Age	
<35 years	7 (15)
35 – 44 years	8 (17)
45 – 54 years	15 (32)
55 – 64 years	12 (26)
>64 years	5 (11)
Sex	
man	26 (55)
woman	21 (45)
Number of treated patients who died in previous 12 months prior to the interview	
none	0 (0)
1-5 patients	2 (4)
6-10 patients	7 (15)
> 10 patients	38 (81)
Number of CDS performed in previous 12 months prior to the interview	
none	0 (0)
1-5 patients	14 (30)
6-10 patients	5 (11)
> 10 patients	28 (59)

*In Belgium, palliative medicine is a medical subspecialty for physicians provided as postgraduate training.

Figure 1. Physicians' experiences and perceptions of the environmental factors affecting their practices of continuous deep sedation until death (CDS). The specific positions of the environmental factors identified at the meso and macro levels in the figure have no intrinsic meaning in terms of influence, but were chosen to make it clear that all factors are intertwined.



Structure: meso

The lack of professional and/or technical support in monitoring sedated patients

Participants hold that monitoring continuously deeply sedated patients is important as it assesses the occurrence of awareness and unbearable suffering. To that end, they often rely on technical and/or professional support in a setting when they cannot carry out the monitoring themselves. In settings with limited or no professionals and/or infrastructure, participants often decide to induce CDS with a higher dose of sedatives than necessary to ensure that patients do not regain consciousness during CDS. Furthermore, some participants hesitate to initiate CDS when there is lack of support, or postpone it. This is true in nursing homes and home settings in particular.

"As I am the physician, I always initiate the first step. And that works well. But it is up to the nurse to actually put their chair next to bed, so to speak, and adjust the doses so that the patient doesn't wake up. You have to act very quickly. So that implies that you need to be with the patient all the time. In a nursing home, CDS cannot go well. Mostly there is only one nurse practitioner responsible for an entire corridor with patients. Here, too, where there is a lack of nurse practitioners, I don't dare to initiate CDS."

-Geriatrician-

The use of guidelines in team contexts

The use of guidelines in team contexts has a "constraining" impact on CDS decision-making of among most participants working in a team context, such as in hospital settings. Some participants say that their teams use existing or modified guidelines for CDS, for example the guidelines for palliative sedation of The Federation of Palliative Care Flanders, to steer the practice of its team members. These guidelines stipulate in detail how the decision-making and performance of CDS "must" be done. Consequently, participants indicate that they sometimes adjust their CDS practice in accordance with these guidelines, even when the instructions in the guidelines are not appropriate for some cases. The constraining impact especially originates from their accountability to the team for deviating from the guidelines. In this regard, some participants point out that they have to report in detail to the team each time when they did not adhere to the guidelines.

The time constraints for treating individual patients and pressure of work

Several participants, especially those with a background in general practice, indicate that “time and performance pressure” occasionally hinders them from carrying out CDS in the way they initially intend to. More specifically, the pressure sometimes “compels” these participants to initiate CDS with a high dose of sedatives to shorten the overall duration of CDS, since “time-consuming” monitoring after proportional initiation is impossible. They believe that government policy provoked this pressure of work: specifically, the health financing system requires physicians to treat “as many patients as possible in the shortest possible time”.

"On the one hand, there is this extensive guideline. Firstly, it take some time to read it. Secondly, it devotes many pages to the conditions of CDS. This is explained in great detail. Then there is a short summary, which mainly focuses on the dosages in which starting schedule is added. The drugs have to be monitored every two hours. In practice, this is not always that easy. Monitoring CDS the way we are supposed to according to the guidelines. As a general practitioner, you lose a lot of time. You have to check the patient regularly during the CDS. That is not always possible in practical terms. Especially since they want us to treat more and more patients. So it is a matter of increasing the doses sometimes.”

-General practitioner-

Structure: macro

The structural knowledge gap in medical education

Nearly all participants claim that medical education does not focus on CDS. Furthermore, the lack of education has yielded a “structural knowledge gap” about CDS in the overall physician population. Therefore, they experience that this gap leads physicians to make “recurring errors” in terms of decision-making about and performance of CDS. Frequently cited errors include the use of suboptimal drugs and initiating CDS with the “incorrect intention”, namely not for mitigating the unbearable suffering.

"There is insufficient training for CDS and also insufficient knowledge. I have never had training on palliative sedation either. I never had anything about palliation. So a lot of doctors do not know what CDS means. Whatever their background is, they just think: “We will give them a bit of Midazolam and they will sleep. If

it needs to go a bit faster? Then we should give them a bit more. After that, we add a little morphine. They think that CDS is pretty simple.”

-Geriatrician-

The legal context for assisted dying

Several participants experience that a certain group of fellow physicians sometimes perform CDS to “intentionally” hasten the death of patients at the end of life instead of performing assisted dying, to circumvent the procedural safeguards of the assisted dying legislation, because these are perceived as “complex” and “burdensome”. In addition, some participants report that they have exceptionally carried out CDS to hasten death in patients for whom a legal framework regarding end-of-life decisions is lacking, but only at patients’ or their proxies’ repeated requests, such as in patients with a severe decline in mental capacity.

"There are also a number of questions in that registration document about assisted dying that are not always easy to answer, for example, that you have to specify what exactly is unbearable suffering. That is one thing. And then there is the practical side of the registration. You have to take it to the post office. You have to send it by registered mail.. You have to register all of this in your patient file. In itself, that is quite a lot of work for something in which we have already invested a lot of time and energy. And I know that many general practitioners often think: “You know, I have really invested a lot of time, energy and effort for this, for which I have been paid little or nothing. But I also have to spend another half hour filling in the paperwork for the registration and another half hour going to the post office to get everything done, waiting in line and so on.” I also notice that colleagues ask questions about this and that this is a barrier preventing them from doing it. And then sometimes CDS is chosen."

-General practitioner-

The lack of a clear legal context for CDS

Some participants argue that the “lack of a clear legal context for CDS” influences their decision-making and performance of CDS, as there is no legal basis for the elements it must include. Therefore, these participants perceive they have more room for interpretation regarding indications for CDS. Furthermore, some participants rely on the French legal context for CDS i.e., the Claeys-Leonetti Law, to guide their CDS decisions. More specifically, they feel supported by the legislation to initiate CDS at patients' explicit requests when most indications are fulfilled.

"I think it is desirable for there to be legislation on CDS and for it to be written a bit like a guideline of how to carry things out, that you have to start at a certain dose depending on the weight of the patient, and that you then have to re-evaluate and document whether the patient is comfortable or not, and that you may then adjust the drugs proportionally. I think everyone has their own method now, because there is very little that is clear and black-and-white due to the lack of legislation."

-Intensive care physician-

Culture: meso

The moral reservations of care teams and/or institutions towards CDS

Several participants explain that they often "hesitate" to perform CDS as their care teams and/or institutions are reluctant to practice CDS. This reluctance partially stems from the moral reservations of these care teams and institutions towards CDS, considering it "morally pernicious" as they believe that physicians mainly use it for terminating patients' life rather than for alleviating unbearable suffering. Given these moral reservations, some of these participants have not performed CDS in some cases despite their belief of being the best option for the patient, or they have not sedated the patient as deeply as they should have done.

"The annoying thing is that you always get caught up in all those ethics. Some physicians say: "You cannot do that. Being so deeply sedated? And is that ethically acceptable?" So yes, in that case I try to find the middle ground based on what I know from all the fields. And searching, and gaining experience. For example, I consult the professionals from intensive care, to achieve something that is acceptable for me, but also for them. How should I put it? Intellectually acceptable. But yes, in the end, the patient is not deeply sedated."

-Palliative care physician-

The presence of a palliative care culture within care teams and institutions

According to most participants, those with training in palliative medicine as well as those without, the presence of a palliative care culture within their care team and/or institution facilitates their own performance of CDS. Palliative care culture is described by participants as the systematic use of palliative care by the care team and/or institution. Due to this palliative care culture, these participants feel encouraged to carry out CDS as palliation against refractory symptoms.

"The biggest difference I see is in the nursing home where I am involved. I think we have a good palliative culture there, and we have also had a palliative care coordinator for the last year who was brought in solely for palliative care. We certainly give all the information about palliative care and CDS. So if you ask, "does everybody know what CDS entails?", then it is certainly the intention for all our nurses to know what it means. When CDS is initiated, the coordinator will take the lead and support me and the nurses who sometimes take over the monitoring, but he will also support the resident's family. That makes you feel, of course, as a GP, that you're working in a medically authorized way and that makes things much easier."

-General practitioner-

The culture of fear of making clinical errors regarding CDS among a group of physicians

Several participants experience that a "culture of fear" is present among a group of physicians surrounding clinical errors regarding CDS. More specifically, this group of physicians is fearful of administering CDS to patients who are not eligible for it in terms of not meeting all the required indications. The fear of these physicians stems from their common perception that CDS has "far-reaching" consequences for patients and their proxies, such as the inability to engage in social interaction. Because of this culture of fear, these physicians occasionally decide not to perform CDS.

The professional stigma of performing assisted dying among some of the physician population

Several participants explain that they have used CDS in part to end the lives of patients, rather than assisted dying, because of the professional stigma of performing assisted dying among some of the physician population. More specifically, this professional stigma means that performing assisted dying is viewed as physicians choosing the "easiest option" to end the suffering of patients. Because these participants do not wish to be associated with this, they sometimes use CDS in cases where they would otherwise use assisted dying.

“And then this ‘compromise’. Yes, I think that this is often done. I have already experienced situations in which I discuss a case with medical specialists about a patient with cancer who had requested assisted dying and they say: “No, we really cannot do that. And if the suffering gets too severe, then we can always do CDS.” So then this compromise is chosen. There should be a chance to be able to talk about life-shortening actions without coming before this ‘moral court’."

-General practitioner-

Culture: macro

The different understandings of CDS in the medical and policy fields

Some participants experience different understandings of CDS in the medical field that impact their practice. These understandings include the notion that CDS should be approached either as a standard practice or an exceptional one. According to these participants, the tension between these understandings in the medical field is reflected in a ”jumble” of different indications, intentions, recommendations, and prudence surrounding CDS. Moreover, some participants report being hesitant and/or cautious to perform CDS as it is viewed as an exceptional practice. Other participants, on the contrary, feel “empowered’ to perform CDS as it is standard practice. According to the participants, this tension is also present in the field of policy. Here, they frequently refer to the ongoing policy debate about whether or not to implement control measures for CDS in Belgium.

The societal taboo around suffering at the end of life and natural death

Some participants often encounter pressure from patients and proxies to initiate CDS at the end of life. Participants attribute this pressure they experience to the societal taboo around suffering at the end of life, resulting in the fear of natural death and suffering in patients and their proxies. Because of this fear, they request CDS, as being sedated is deemed as a “painless and peaceful way to die”. Consequently, participants indicate giving in to such pressure in certain cases, although some patients do not fulfill the whole range of indications for CDS.

“That sometimes CDS is initiated too early is also due to pressure from the families. “And look at him lying here now. That is not good, let him sleep now.” And then, as a physician, you hit a bit of a wall and sometimes the dose is increased abnormally or other things are done with the intention of speeding things up. But then that is not always what was initially intended. But it is very often under pressure from our

society that these things happen. We are not always used to seeing people die. But maybe that is a reality that we have to learn to deal with as physicians? And, yes, dying, they want you to keep people alive for as long as possible. But you should not talk about it too much. You should not do too much advanced care planning. But when they lie there. You cannot do that. That is not possible. Yes, it has to be 'done' yesterday rather than today. And that is the current society in which we are living nowadays."

-Intensive care physician-

Discussion

Summary of main findings

We aimed to explore physicians' experiences and perceptions of environmental factors affecting CDS practice. Multiple environmental factors were identified that could be centered around culture and structure. Firstly, structural factors include 1) the lack of professional and/or technical support in monitoring sedated patients; 2) the use of guidelines in team contexts; 3) the time constraints for treating individual patients and pressure of work; 4) the structural knowledge gap in medical education; 5) the legal context for assisted dying, and 6) the lack of a clear legal context for CDS. Secondly, cultural factors include 1) the moral reservations of care teams and/or institutions towards CDS; 2) the presence of a palliative care culture within care teams and institutions; 3) the culture of fear of making clinical errors regarding CDS among a group of physicians; 4) the professional stigma of performing assisted dying among some of the physician population; 5) the different understandings of CDS in the medical and policy fields; and 6) the societal taboo around suffering at the end of life and natural death.

Strengths and limitations

Since the influence of the environmental context on the practice of CDS has rarely been addressed by previous research, our secondary represents an important contribution to the body of literature. All the researchers of the primary study were involved in the process of secondary analysis, and thereby being closer to the research subject, the study context, and the primary data.[25,31,51] By doing so, we enhanced the clarity and trustworthiness of the secondary study. For example, a misinterpretation of the methods used in the primary study was not possible.[52] Additionally, the primary data have been collected recently. Therefore, it is most likely that the findings of our secondary analysis still apply to the current context of

CDS practice.[27,31] The sample of participants shows a considerable degree of heterogeneity, which allowed us to include different perceptions and experiences in the analysis.

Performing a secondary study also entails some limitations. The use of a secondary design is a limitation in that the topic guide was not specifically geared to the research questions in this article. This may have led us to miss relevant information. Although theoretical sampling of participants was not possible to enhance the rigor of the secondary analysis, we argue that this limitation has been moderated by including a maximum variation of physicians' experiences and perceptions in the analysis.[29,31] Although our 'closeness' to the primary study involves several opportunities, this simultaneously hinders a 'tabula rasa' approach in performing a secondary analysis.[27] Furthermore, environmental factors were identified with the aid of physicians' experiences and perceptions. Therefore, we may not have captured the whole (inter)subjective complexity of the environmental context as other parties involved were not included. In addition, we employed investigator triangulation, namely including multiple researchers in the whole process of analysis, to reduce potential bias.

Interpretation of the findings

In general literature, the medical practice of physicians is assumed to be bound to the ever-changing and dynamic context, thus not merely being the results of individuals' cognitive processes.[53,54] With regard to CDS practice, this assumption is also echoed by the narratives of participants in our study, indicating that the environmental context influences physicians' practice of CDS. In this way, our findings could be interpreted as an empirical substantiation for the assumptions of several authors that the environmental context plays a non-negligible role in CDS. Although authors especially suggest the potential influence of culture,[4,55] structure should not be overlooked to understand the full scope of factors influencing CDS practice, as multiple structural factors have been identified in our study while these have often been omitted by research. By identifying environmental factors, our study might provide additional explanations for the considerable variation in the prevalence and practice of CDS between settings and countries.[5] The latter, for instance, is reflected in the international UNBIASED Study conducted in the Netherlands, Belgium, and the United Kingdom.[9,10] That study showed that CDS could refer to a spectrum of practices, or variation in CDS practice, which was mainly attributed to the differences between practitioners themselves in these countries, such as differences in their personal attitudes towards CDS and conceptualizations of CDS.[8] Our findings suggest that such variation in CDS practice may not only be attributed to (inter)personal factors, but simultaneously to meso and macro factors. In that regard, some meso and macro factors identified could also be interpreted as facilitators that might prompt physicians' use of CDS, namely, the presence of a palliative care culture within care teams and institutions, the shared understanding of CDS as a normal practice, the assisted dying legislation, and the societal fear of suffering at the end of life. Thus, hypothetically, these factors may partly explain why the prevalence of CDS in Belgium is considerably higher than in other countries.[5]

Our study suggests that the practice of CDS is empirically intertwined with the practice of assisted dying, which corroborates previous studies.[9,56–62] More specifically, our findings indicate that in some cases, consideration of assisted dying is diverted to CDS due to the professional stigma of assisted dying among some of the physician population, the procedural requirements of the assisted dying legislation, and the gaps in this legislation in terms of excluding certain patient groups. This environmental context thus seems to influence CDS practice, leading to CDS being opted for more often as well as potentially being carried out with an intention to actively hasten death. In literature, reference has been made in that regard to 'hidden assisted dying', 'slow assisted dying', and 'grey area practice'.[4,63] Empirical studies, however, locate the causes of such intertwining in physicians in particular: for example in their moral identities,[9] or their lack of an accurate notion of CDS and/or assisted dying.[58] Our findings, by contrast, suggest that the empirically close relationship between CDS and assisted dying is also determined through structural and cultural factors on the meso and macro level. In that regard, some participants in our study indicated the legal context for assisted dying in particular as a predominant macro factor of influence. This might contain important implications for those jurisdictions seeking to implement legislation on assisted dying. As such implementations can be accompanied with a change in how CDS is framed and approached both medically and societally, it is advisable for these jurisdictions to consider this potential change in their implementation process, anticipating its effects.

Recommendations and implications

As the practice of CDS is believed to have room for improvement, various quality improvement initiatives have been developed in the medical field that have had little impact.[22] In accordance with our findings, it can be recommended that such initiatives should also address the environmental context of physicians in order to enhance their leverage. Guidelines for CDS, for instance, could also pay attention to how practitioners can deal with the pressure from patients and their proxies to perform CDS, or cope with their possible fear of making clinical errors in relation to CDS. Alternatively, guidelines for CDS that make a clear distinction between assisted dying and CDS may aid physicians to better differentiating both from each other in practice.

The criticism of CDS has led public health policymakers in some countries, such as Belgium and the Netherlands, to consider improving CDS practice as a whole.[63] This study provides indications of which aspects to target. A first step in that direction might be that public health policymakers and the medical field work together to clarify the conceptual ambiguity regarding CDS. It also seems appropriate that they apply a contextual approach adapted to the real-life experiences of physicians to address the identified environmental factors that lead them to consider CDS as a substitute for assisted dying. Profound instruction about CDS in medical training is also a worthwhile recommendation.

Future research could investigate to what extent our findings about the influence of the environmental context apply to countries without legislation on assisted dying. Another interesting research direction would be to investigate how and to what extent the implementation of cultural and structural elements in improvement initiatives would enhance CDS practice. Moreover, we only used the experiences and perceptions of physicians to explore environmental factors impacting CDS practice. Therefore, it may be interesting for future studies to explore the experiences of other parties involved, for example of, nurses, to shed light on another part of CDS practice and to compare their accounts of environmental factors with our findings. Furthermore, further research is also needed on how micro factors in physicians' practices of CDS are related to meso and macro factors we have identified in this study.

Conclusion

Based on physicians' experiences and perceptions, this study suggests that multiple environmental factors might affect their practice of CDS. This indicates that the environmental context should be considered to grasp the whole reality and scope of influence of CDS practice. The factors identified here could provide guidance to those who want to steer or intervene in physicians' practices of CDS, underlining the need to move beyond physicians' personal and interpersonal characteristics. Our findings emphasize the importance of adopting a whole-system approach to improve CDS practice as a whole.

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PART IV

General discussion

Chapter 8

Interpretation and implications of dissertation findings

Introduction

The aim of this dissertation was twofold, namely, 1) to describe current practices of control and support in euthanasia and to explore their potential for improvement in Flanders and Brussels (Part 1), Belgium, and 2) to describe current practices of control and support in CDS and to explore their potential for improvement in Belgium. To address these aims, we undertook four studies, each accompanied by its own data collection process. In the first study –i.e., LEIF Study-, we studied the experiences of attending physicians and LEIF consultants regarding their peer consultations for a euthanasia request assessment. In the second study –i.e., Support Needs Study-, we explored the support needs of patients requesting euthanasia and their relatives throughout their euthanasia trajectories. In the third study –i.e., Good Practices Study-, we explored the good practices that HCPs deploy and identify in euthanasia practice. In the fourth study, we examined physicians' frames of control measures for CDS, and their perspectives and experiences regarding the environmental factors affecting their CDS practices.

In the subsequent sections, we will summarize the main findings, discuss methodological considerations, including the strengths and limitations of our studies, provide an interpretation of dissertation findings, and propose implications and recommendations for practice, policy, and research.

Summary of main findings

We sought to answer the following research questions in this dissertation:

Describing current practices of control and support in euthanasia and exploring their potential for improvement (Part I):

Chapter 2: A) What are the characteristics and outcomes of peer consultations for a euthanasia request assessment, and their influence on euthanasia, as reported by attending physicians?;

B) What are the influences of these characteristics and outcomes of peer consultations on the performances of euthanasia, as reported by attending physicians?

Chapter 3: What are the (quality) characteristics and their changes over time of peer consultations for euthanasia request assessments, and changes over time in these characteristics, as reported by trained assisted dying (LEIF) consultants?

Chapter 4: What support needs do patients requesting euthanasia and their relatives experience throughout their euthanasia trajectories?

Chapter 5: Which good practices do healthcare professionals deploy in euthanasia practice?

Describing current practices of control and support in CDS and exploring their potential for improvement (Part II)

Chapter 6: How do physicians frame control measures for continuous deep sedation until death?

Chapter 7: What are physicians' experiences and perceptions of environmental factors affecting their practices of continuous deep sedation until death?

Describing current practices of control and support in euthanasia and exploring explore their potential for improvement (Part I)

Chapter 2 describes the cross-sectional survey study conducted among attending physicians who had consulted a LEIF consultant for a euthanasia request assessment. Our final sample for data analysis comprised 502 attending physicians, representing a valid response rate of 56% (502/903). Our findings revealed that the vast majority of attending physicians were general practitioners (92%). Among the consultations for a euthanasia request assessment, more than half involved patients diagnosed with cancer (57%), while 66% of patients were aged 70 years or older. The reasons most often cited by patients for requesting euthanasia were suffering without the prospect of improvement (49%), loss of dignity (11%), pain (9%), and tiredness of life (9%). In the vast majority of consultations (85%), attending physicians consulted the LEIF consultant due to their expertise. In nearly half of the consultations (46%), they consulted the LEIF consultant because of their independence (a legal requirement). In 91% of consultations, the consultants provided positive advice, i.e., the patient met the substantive requirements. Euthanasia was carried out in eight out of ten consultations (80%). We found that the likelihood of euthanasia being performed was higher in consultations in which loss of dignity, loss of independence in daily living, or general weakness or tiredness were reasons for requesting euthanasia, as compared to consultations in which these reasons were not reported. Moreover, consultations involving patients with a psychiatric disorder were found to be less likely to result in the performance of euthanasia, compared to consultations involving patients with cancer. We concluded that the peer consultation practice with LEIF consultants seems to be mainly integrated within primary settings. Furthermore, our study supports the trend found by previous research that euthanasia is relatively less prevalent among patients with cancer, while relatively more prevalent among patients with general deterioration. In addition, our study further highlights that attending physicians deploy peer consultations with LEIF consultants as a resource to meet their support needs regarding euthanasia practice, but also to reinforce their own decision-making regarding the euthanasia request.

Chapter 3 reports on shifts found between the cross-sectional survey studies that we conducted in 2008 and 2019 among LEIF consultants who had participated in a peer consultation for a euthanasia request assessment. Our final study sample in 2008 included 71 LEIF consultants (i.e., a valid response rate of 75%, 96/128), and 141 LEIF consultants in 2019 (i.e., a valid response rate of 57%, 226/400). In 2019, compared to 2008, there was a significant increase in the proportion of LEIF consultants who were below the age of 40 years (25% in 2019 vs. 10% in 2008, p=0.006) and those who were at least 60 years old (34% in 2019 vs. 20% in 2008, p=0.006). As for their activities related to assessing euthanasia requests over 12 months, we found a significant decrease in the proportion of patients who did not meet the substantive requirements for euthanasia in 2019 compared to 2008 (42% in 2019 vs. 60% in 2008, p=0.020). In their most recent euthanasia request assessments, LEIF consultants conducted significantly more assessments for patients aged 80 years or older than in 2008 (31% in 2019 vs. 9% in 2008, p<0.002). Conversely, there was a significant decrease in the proportion of assessments for patients with cancer (53% in 2019 vs. 70% in 2008, p=0.034). As for adhering to quality criteria for consultation in their most recent assessments, LEIF consultants in 2019 dealt with the following topics significantly more often than in 2008: unbearable suffering (87% in 2019 vs. 65% in 2008, p=0.003) and alternative treatments, including palliative care (48% in 2019 vs. 13% in 2008, p<0.001), and curative treatments (28% in 2019 vs. 5% in 2008, p=0.002). We suggest that the identified changes in our study likely correspond to broader changes in euthanasia practice. Furthermore, our findings suggest that attending physicians are increasingly seeking consultations with LEIF consultants for complex cases, in contrast to the initial years following the implementation of euthanasia legislation. Also, our findings suggest improved adherence to quality criteria for consultation among LEIF consultants, potentially reflecting increased awareness of these criteria.

Chapter 4 explores the support needs that patients requesting euthanasia and their relatives experience throughout their euthanasia trajectories. To that end, we used a qualitative approach, including semi-structured interviews and written narratives. Our study sample comprised 26 research participants: 15 patients who requested euthanasia and 21 relatives. In total, we identified eight types of support needs. First, patients needed support for maximizing daily functioning, such as aid with transportation. This support was seen as vital for maintaining their self-worth and enabling them to remain independent at home in order to receive euthanasia. Second, relatives needed support in understanding the patient's desire for euthanasia. This support was seen as a way to facilitate closure, accept the patient's desire for euthanasia, and evaluate their own role in alleviating the suffering. Third, participants needed support for managing meaningful activities to maximize their remaining time together and give purpose to their euthanasia trajectories, for example, support for organizing a farewell ritual. Fourth, participants needed support for navigating existential questions, as these questions could lead to feelings of loneliness and distress. Fifth, participants needed support for psycho-emotional regulation, as intense and fluctuating emotions often characterize their euthanasia trajectories, such as anxiety, distress, and fear. Sixth, participants needed support for facilitating social interaction. Participants required this support to resolve social conflicts, improve social bounds, enhance communication with loved ones, and facilitate family engagement. Seventh, participants needed support for understanding the process toward euthanasia. This support would provide them with a better comprehension of the euthanasia legislation and procedure, and of the attending physician's decision-making regarding euthanasia. Eighth, participants needed support for handling organizational and practical matters. This support was seen as a way to alleviate the burden of organization and practical tasks of euthanasia practice, allowing them to prioritize more important aspects, such as social activities. Our study highlights that patients requesting euthanasia and their relatives experience multidimensional support needs in euthanasia practice. Moreover, our findings suggest that they rather experience euthanasia practice as a social-existential process than as a medical one. We conclude that the support needs of patients and relatives essentially correspond with multidimensional palliative care needs. Hence, we argue that euthanasia support for patients and relatives might benefit from a palliative care approach to meet their support needs.

Chapter 5 entails a qualitative study conducted with healthcare professionals (HCPs) to explore the good practices they identify and deploy in euthanasia practice. Our data collection involved semi-structured interviews, focus groups, and an expert panel discussion (with HCPs with advanced expertise in euthanasia practice). We included 64 HCPs in our study: 25 physicians, 18 nurses, 9 psychologists, 7 social workers, and 5 case managers. Our analysis revealed seven themes. Each theme represents an overarching good practice, a broad principle, or an approach that underlies various good practices. We identified 28 good practices. The first theme concerns patient-centeredness, including the following good practices: a) continuously assessing and meeting patients' needs and preferences, b) safeguarding patient autonomy, c) psychosocial support for patients, and d) spiritual-existential support for patients. The second theme centers on family-centeredness, including the following good practices: a) continuously assessing and meeting relatives' needs and preferences, b) actively involving relatives, c) special attention to children and young adults, d) facilitating communication between patients and relatives, e) psychosocial support for relatives, f) anticipatory grief and bereavement care for relatives, and g) spiritual-existential support for relatives. The third theme focuses on safeguarding the psychosocial well-being of HCPs, including the following good practices: a) self-care, and b) special attention to the psychological well-being of colleagues. The fourth theme revolves around managing expectations in patients and relatives, including the following good practices: a) developing euthanasia literacy in patients and relatives, b) developing euthanasia preparedness in patients and relatives, and c) establishing clear arrangements with patients and relatives. The fifth theme concerns carefulness, including the following good practices: a) continuity of support, b) professional preparedness for the performance of euthanasia, c) carefulness in assessing eligibility for euthanasia, d) medical-technical carefulness, e) serenity during the performance of euthanasia, and f) professional knowledge and skills about euthanasia. The sixth theme focuses on a multidisciplinary approach, including the following good practices: a) multidisciplinary collaboration, b) clear communication between HCPs, and c) consulting and involving special expertise. The seventh theme revolves around compassionate, proactive, and communicative HCPs, including the following good practices: a) being a compassionate HCP, b) being a proactive HCP, and c) being a communicative HCP. Our findings indicate that HCPs identify and deploy a multitude of good practices in euthanasia practice. Most good practices relate to specific actions and methods, while others relate to the attitudes of HCPs. We conclude that HCPs could enhance their euthanasia practices by adopting a non-medical approach that considers the social, existential, and psychological aspects of euthanasia.

Describing current practices of control and support in CDS and exploring their potential for improvement (PART II)

Chapter 6 concerns the interview study conducted with physicians having lived experience with the CDS practice to identify how they frame control measures for CDS. We performed semi-structured interviews with 47 physicians. While participants generally agreed on the need for specific action to improve CDS practice, their views and reasoning varied considerably regarding the types of problems existing in CDS practice, problems behind these problems, the value judgments of CDS practice, and the solutions and action to improve CDS practice, such as the control measures for CDS. We identified five frames that form the basis for these variations in physicians' views and reasoning. The first frame concerns 'control through expertise', in which physicians propose expert consultation and training and/or education to improve CDS practice. The second frame focuses on 'strict due care', in which physicians put forward registration of CDS and shared decision-making to improve CDS practice. The third frame involves 'safeguarding patient choice', in which physicians advocate for having the legal option to initiate CDS to accompany the dying process of patients to improve CDS practice. The fourth frame centers around 'facilitating dignity', in which physicians propose to legally protect physicians who initiate CDS to facilitate a dignified dying process for patients with a severe loss of mental capacity to improve CDS practice. The fifth frame concerns' improving communication', in which physicians advocate for refining and improving physicians' communication skills and raising public awareness to improve CDS practice. Our study indicates tension among physicians regarding suitable solutions and actions to improve CDS practice. Some advocate for professional self-regulation, while others for state governance. We concluded that physicians' frames should be considered to develop effective control measures and/or actions to improve CDS practice.

Chapter 7 involves a secondary analysis of the data collected in our interview study with physicians having lived experience with CDS practice (Chapter 6) to explore their experiences and perceptions of the environmental factors affecting their CDS practices. For our data analysis, we used the complete data of the 47 physicians who were included in our primary study. Overall, we identified two types of environmental factors affecting the CDS practices of physicians. First, we identified structural factors on the meso and macro level: the lack of professional and/or technical support in monitoring sedated patients; the use of guidelines in team contexts; the time constraints for treating individual patients and work pressure; the structural knowledge gap in medical education; the legal context for assisted dying; and the lack of a clear legal context for CDS. Second, we also identified cultural factors on the meso and macro level: the moral reservations of care teams and/or institutions towards CDS; the presence of a palliative care culture within care teams and institutions; the culture of fear of making clinical errors regarding CDS among a group of physicians; the professional stigma of performing assisted dying among some of the physician population; the different understandings of CDS in medical and policy fields; and the societal taboo around suffering at the end of life and natural death. Our study suggests that multiple environmental factors might affect the CDS practices of physicians. Therefore, we concluded it might be worthwhile considering a system approach to improve CDS practice as a whole.

Methodological considerations

To answer the research questions of this dissertation, we applied two types of methodologies over four studies. First, we applied quantitative methodology in the LEIF Study (Chapters 2 and 3), in which we used cross-sectional surveys (written and online questionnaires) to capture the experiences of attending physicians and LEIF consultants. Second, we applied qualitative methodology in the Support Needs Study (Chapter 4), the Good Practices Study (Chapter 5), and the CDS study (Chapters 6 and 7), using semi-structured interviews, written narratives (through qualitative questionnaires), focus groups, and an expert panel discussion to capture the experiences and views of patients requesting euthanasia, their relatives, HCPs with lived experiences of euthanasia practice, and physicians with lived experiences of CDS practice.

Hence, an overall strength of this dissertation is that we employed a multimethod approach, including quantitative and qualitative methodologies, combined with a multi-perspective approach, including the perspectives of various stakeholders involved in the practices of euthanasia and CDS, e.g., patients, relatives, physicians, and other HCPs. By using methodological triangulation (multimethod approach) and data source triangulation (multi-perspective approach), we addressed our research aims from different angles. This allowed us to gain richer insights as we obtained a more comprehensive and holistic understanding of the practices of euthanasia and CDS compared to merely using one methodology and/or the experiences of one stakeholder group.[1,2] Furthermore, these forms of triangulation improve the credibility, validity, and reliability of our findings.[1] Also, we applied investigator triangulation across all our studies. Multiple researchers were involved in developing the research design, data collection, data analysis, and reporting of the findings. These researchers had different backgrounds, including sociology, ethics, health policy, and social work, which resulted in adapting a multidisciplinary research lens. They convened through bimonthly group meetings to discuss and reflect upon the studies of this dissertation. By adopting investigator triangulation, we sought to decrease researcher and interpretation bias, thereby increasing the validity and reliability of our findings.[1] Another overall strength is that this dissertation delves into topics that are under-researched in the literature, namely, the support needs of patients requesting euthanasia and their relatives, good practices in euthanasia practice, control measures for CDS, and environmental factors affecting. In this way, we also aimed to respond to the calls of research scholars who have emphasized the importance of exploring these issues in greater depth. Finally, we believe that the insights of this dissertation can be valuable to individuals and entities seeking to improve their practices of euthanasia and CDS, such as patients, relatives, physicians, other HCPs, healthcare organizations, the wider public, and jurisdictions.

An overall limitation of this dissertation relates to external validity, as it is difficult to determine the transferability of our findings to euthanasia and CDS practices beyond the contexts of Flanders and Belgium. The studies on euthanasia practice only involved research participants from Flanders and Brussels, the Dutch-speaking part of Belgium. As for the study on CDS practice, research participants were recruited across Belgium. In other words, our research participants are part of a particular context that might have influenced their experiences and views of these practices. This was also highlighted in Chapter 7; namely, that structural and cultural factors influence CDS practice. Noteworthy contextual factors that could have shaped their experiences (and are somewhat unique to the Belgian setting) are, for example, palliative care policy, the health care system, the organization of the welfare state, ethical and societal norms surrounding euthanasia and end-of-life care, professionalism among physicians, the education system for HCPs, and the social security system. However, we firmly believe that our findings hold a certain degree of transferability to other contexts. Dismissing transferability would reflect an extreme form of cultural relativism. Furthermore, it is important to emphasize that our primary aim was to achieve theoretical generalization regarding euthanasia and CDS practices as phenomena rather than making statistical generalizations about specific populations.

Each study conducted also has its own specific strengths and limitations. We will elaborate upon these in the following sections.

LEIF Study: cross-sectional survey studies

A first strength of this study (Chapters 2 and 3) is that we focused on the characteristics of peer consultations in the context of euthanasia. By doing so, we believe that we embarked upon an under-researched topic, as the vast majority of previous studies have mainly focused on the characteristics of euthanasia performances. A second strength of our cross-sectional survey study is that we obtained relatively high response rates. In our studies among LEIF consultants, the response rates were 75% in 2008 and 57% in 2019. In our study with attending physicians, the response rate was 56%. This is rather exceptional, considering that physician surveys are known to obtain relatively low response rates.[3] A third strength includes that our data collection was informed by the robust Dillman's Total Design Method to maximize the response rate by employing four follow-up rounds.[4] A fourth strength is that physicians could participate in our study by completing the 2019 questionnaire either online or on paper, which most likely increased the response rate. A fifth strength is that we only collected data on the most recent peer consultations of attending physicians and LEIF consultants to minimize the potential impact of recall bias. A specific strength of the study among attending physicians is the repetitive nature of the cross-sectional surveys: a pseudo-longitudinal design. This means that we used the same method and measure instrument (questionnaire) for both surveys. So by using similar questionnaires in 2008 and 2019, we gathered data at two points in time, allowing us to make valid comparisons over time to identify changes. A specific strength of the studies among LEIF consultants is that the surveys were sent to the full population of consultants. As such, we sought to anticipate possible sampling bias.

Several limitations intrinsic to cross-sectional surveys should be considered. First, there could have been a possible non-response bias. For example, it is possible that we received a lower response from physicians who experienced time constraints during the moment of data collection compared to those who did not. This was partly confirmed by our non-response survey among LEIF consultants in 2019, in which time constraints were the most often reported reason for non-participation in the study. However, we mitigated this by extending the data collection process up to six months. Second, the retrospective design of our study may have resulted in recall bias. This could have resulted in, for example, less accurate reporting of information. Third, a possible rater bias (which refers to second-hand reporting) cannot be excluded as we relied on physicians' perspectives to report on patient information –e.g., their reasons for requesting euthanasia-; and not patients' perspectives. Also, pertinent to Chapter 3, we used data from the 2008 sample of attending physicians to compare adherence to quality criteria for consultation among LEIF consultants, which might have led to rater bias. Fourth, social desirability bias can be possible as euthanasia can be deemed as a sensitive topic, resulting in answers that align with socially desirable or acceptable answers rather than reflecting their true experiences. For example, it is plausible that physicians reported adherence to legal requirements in the questionnaire, while this was not the case in practice. A specific limitation in Chapter 2 is that our data collection was restricted to attending physicians having consulted a LEIF consultant who had received financial compensation from the National Institute for Health and Disability Insurance (NIHDI) for their consultation. This might have led to some ascertainment bias.

Support Needs Study: semi-structured interviews and written narratives

A first strength of this qualitative study (Chapter 4), including semi-structured interviews and written narratives (through qualitative questionnaires), is that we captured the lived experiences of patients requesting euthanasia and their relatives. These persons are essential actors in euthanasia practice and are under-researched groups. Previous studies have mainly reported second-hand accounts to describe the experiences of patients, such as the accounts of their attending physicians and other HCPs. As such, we conducted one of the few studies worldwide that involved persons requesting euthanasia as research participants. Our qualitative design was well suited to explore their support needs –a relatively new research topic- as it enabled us to gain a comprehensive understanding of their experiences and the specific contexts in which these experiences are embedded. A second strength is that we also utilized written narratives through qualitative questionnaires to collect data from patients requesting euthanasia. By doing so, we intended to increase the probability of including those patients being more reluctant and/or unable to participate through an interview, thus anticipating possible recruitment bias. A third strength concerns that we obtained data saturation, following the principles of inductive thematic saturation.[5] More specifically, we did not find new meaning regarding the identified themes after analyzing the 26th interview.[5] Most likely, this data saturation can be attributed to the large sample of participants (for qualitative research) and the variation in the profiles of these participants. A fourth strength is our flexibility in conducting in-person or online interviews according to participants' preferences. We offered both options to participants in response to the COVID-19 pandemic. This was implemented to address potential recruitment bias by ensuring that individuals who were more apprehensive about the risk of a COVID-19 infection would not be recruited. A fifth strength lies in our recruitment strategy, in which we utilized a self-developed website. This website served as a comprehensive platform to inform potential participants about various aspects: the research aims and methods, the different options for study participation, the informed consent, the main themes of the topic guide, the applicability of the study results, the research team, ensuring their anonymity after study participation, and how to access free psychological support following study participation. With this form of transparency, we intended to reduce possible barriers to study participation. A sixth and last strength is the high number of research participants. In total, we included the lived experiences of 36 participants in our final study sample. This provided us with a rich and diverse dataset, enhancing the depth of our insights.

A first limitation concerns a potential motivation bias (a specific type of self-selection bias). We acknowledge the possibility that participants who self-selected to participate in our study could have had specific motivations, for instance, for sharing their strong need for support in euthanasia practice. However, we sought to mitigate this by including a wide variation in the profiles of participants. A second limitation lies in a possible recall bias and psychological adjustments, for example, resulting in reporting more positive or negative emotions and/or thoughts regarding certain events in the euthanasia trajectory than they actually experienced. A third limitation is potential social desirability bias. Participants might have provided us with socially desirable responses due to the sensitivity of the research topic. This tends to occur more frequently in qualitative research than in quantitative research because of the direct interaction with a researcher.[6] A fourth limitation is that we mainly recruited and included patients with non-terminal conditions and, to a lesser extent, those with terminal conditions. This may be attributed to the fact that these most often receive euthanasia shortly before their anticipated death. Hence, it could be that we did not capture the whole range of the support needs of patients with terminal conditions. However, we believe this to be rather unlikely since we obtained data saturation and included a considerable amount of lived experiences of euthanasia cases involving patients with terminal conditions from the perspectives of their relatives. In this regard, some caution is warranted when assuming the transferability of our findings. A fifth limitation involves that recruitment primarily took place through online channels. Therefore, it is plausible that we recruited and included fewer participants with limited access to these channels and/or are less knowledgeable about using them. One limitation of the written narratives is that we could not probe into specific issues to the same extent as we could in the semi-structured interviews.

Good Practices Study: semi-structured interviews, focus groups, and an expert panel discussion

An overall strength of this qualitative study (Chapter 5) is that we included the lived experiences of a broad range of HCPs, involving physicians, nurses, social workers, psychologists, and case managers. These HCPs are all important actors in the care and support provision in euthanasia practice. This is one of the first studies to explore the good practices that HCPs deploy and identify in euthanasia practice. Conducting this research with participants from Flanders, Belgium, is highly pertinent given the longstanding legal implementation of euthanasia. Consequently, participants from Belgium can be assumed to have a richer foundation of lived experiences of good practices in contrast to participants from jurisdictions that have recently legalized the practice. We conducted semi-structured interviews with physicians, as they are the only HCPs who may legally assess and perform euthanasia in Flanders. Semi-structured interviews offer the general strength that participants can openly and confidentially discuss their euthanasia practices. Also, physicians could address topics that the interviewers did not anticipate, such as the need for a tailored approach to involve children and young adults in euthanasia practice, which was identified as good practice by HCPs (Chapter 5). We performed homogenous focus groups, grouping participants based on their professional backgrounds. Focus groups hold the key strength of fostering the exchange of diverse views and opinions through interactive discussions, enabling participants to highlight differences and similarities.[7] This dynamic interaction facilitates the emergence of salient themes within the group.[7] Moreover, we also performed an expert panel discussion with HCPs with advanced expertise in euthanasia practice. A key strength of an expert panel discussion lies in its capacity to untangle complex study topics –such as euthanasia- by integrating diverse knowledge domains and adding nuanced perspectives to the discussion.[8] Another strength of our qualitative study is that we included 64 HCPs, a relatively high number for qualitative research. This large study sample provided us with rich data to explore the good practices of HCPs. Another strength is that we obtained data saturation of the identified themes across all health disciplines, following the principles of inductive thematic saturation.[5] Another strength is the utilization of the self-developed website for participant recruitment (see above in the strengths in Support Needs Study) as well in this study, which most likely explains our large qualitative study sample. A last strength pertains to using a flexible approach; we provided physicians with the flexibility to conduct semi-structured interviews outside of their regular working hours, including evenings and weekends, to accommodate their preferences.

The limitations discussed in The Support Needs Study, also apply to the Good Practices study. More concretely, we cannot rule out that there might be some motivation bias, psychological adjustments, recall bias, and social desirability bias. Furthermore, possibly, we identified some attitude-based good practices instead of experience-based practices. Therefore, some carefulness is warranted when interpreting and applying the findings. Furthermore, we conducted this study amidst the ongoing COVID-19 pandemic, when HCPs faced increasing work pressure and time constraints. This might have led to potential recruitment bias, for example, mainly recruiting HCPs who were not experiencing time constraints. However, we adopted a flexible approach to mitigate this. First, HCPs unable to participate in a focus group could participate via a semi-structured interview. Second, we extended the participant recruitment and data collection from three to six months. Third, we held the focus groups and the expert panel discussion online. A limitation of online interviewing is that there might be a less personal connection with the researchers (interviewers) than interviewing in person, which might have resulted in participants feeling less inclined to disclose sensitive or personal information. We chose this online approach to minimize time loss due to participants traveling to a physical location and to address concerns about the risk of COVID-19 infection associated with in-person participation.

CDS Study: semi-structured interviews and secondary qualitative analysis

A key strength of this study is that it focuses on two under-researched topics in CDS literature: control measures for CDS and the environmental factors affecting CDS practices. To that end, we included the experiences and the perspectives of physicians, being the most important HCPs in this practice, as most protocols and guidelines postulate that they should carry out the assessment, the monitoring, and the performance of CDS.[9] To examine control measures for CDS ('primary CDS Study'), we conducted 47 semi-structured interviews, providing rich data. A general strength of using semi-structured interviews is that it allows participants to expand on topics that may not have been initially covered in the topic guide. First, this is shown in the fact that we had to modify our initial topic guide, as the first semi-structured interviews had indicated that physicians preferred various control measures, solutions, and actions to improve CDS practice. Second, this is further exemplified by the rich data that we collected on the environmental factors affecting CDS practices. However, this theme was not incorporated into the topic guide. This was partly due to physicians extensively elaborating on their belief that control measures should be tailored to the unique and influential context of CDS practice. For this reason, we decided to perform a secondary qualitative analysis, using the data from these 47 interviews ('secondary CDS Study'). A secondary qualitative analysis is justified when primary data reveal an important issue that has been overlooked by previous research.[10] Moreover, a secondary analysis is especially warranted when the research population, such as physicians, is known to be challenging to recruit.[10] A general strength of the secondary qualitative analysis is its time and cost efficiency using pre-existing data. Another strength concerns that physicians are alleviated from the burden of being interviewed.[10] Furthermore, another strength lies in the fact that the researcher who conducted the primary study also performed the secondary analysis. This familiarity with the dataset ensures a contextual understanding of the data, which, in turn, enhances accuracy.[11] This understanding might have been compromised if the secondary analysis had been conducted by researchers not involved in the primary study.[11] A specific strength of the primary CDS study is that we achieved data saturation, following the principles of code saturation.[12] In the secondary analysis, we reached a state of 'meaning saturation', in accordance with the meaning saturation model of Hennink et al, which is more suitable to determine saturation in a secondary analysis.[12] This saturation point was reached after analyzing 35 interviews, at which we determined that no additional data could enhance our understanding of the environmental factors impacting the CDS practices of physicians.[12] This saturation may be attributed to our large sample of participants and the inclusion of a diverse range of experiences related to CDS practice, which aligns with the quality criteria other research scholars advocate for when conducting a secondary analysis of qualitative data.[5,10,12,13]

Like the qualitative studies around assisted dying, the primary CDS Study has limitations innate to qualitative research. As for the latter, it should be noted that we conducted the interviews during a period of public debate in Belgium on implementing control measures. Therefore, certain physicians may have experienced a higher motivation to participate due to their strong support or opposition to such implementation. Another limitation is that the interviews with French-speaking physicians were shorter, providing us with less rich data than those with Dutch-speaking physicians. Moreover, we should also consider some specific limitations regarding the secondary CDS Study. First, possibly, we did not capture the whole environmental context of CDS practice as this theme was not the main focus of the topic guide in the primary CDS Study. However, it is essential to note that, as our study progressed, we actively explored this specific topic during the interviews as we gradually realized the significance of the environmental context in understanding potential control measures for CDS. Second, although we have argued above that our involvement in the primary CDS Study entails some advantages, it may also introduce researcher bias as a complete 'tabula rasa' perspective is impossible.[10]

Interpretation of dissertation findings

In the following sections, we will provide a further in-depth discussion and interpretation of the main findings of this dissertation in relation to each other and the recent literature.

1. A variety of potential problems and complexities: does it require a multi-solution and more integrated approach?

A key finding of this dissertation concerns that physicians and other HCPs identify and might experience a variety of complexities and problems in their euthanasia and CDS practices **(Chapters 2, 5, 6, and 7)**, which consequently prompts the question whether a multi-solution and integrated approach is required to address these complexities and problems comprehensively. With this approach, we refer to combining various solutions simultaneously ('multi-solution') and aligning them with each other ('integrated') to tackle identified problems and complexities in practice, drawing from current Theories of Quality Improvement.[14] In the subsequent paragraphs, we will discuss the complexities and problems we found across our studies and elaborate on whether we need a multi-solution and more integrated approach.

Our studies on euthanasia indicate that physicians can encounter several complexities in their euthanasia practices. This is supported by the fact that one out of four attending physicians report having consulted a LEIF consultant due to the complexity of the euthanasia request **(Chapter 2)**. This is in line with findings from a study in the Netherlands in which trained SCEN consultants (Support and Consultation on Euthanasia in the Netherlands) perceived 22% of their euthanasia request assessments as complex.[15] Interestingly, we found that these complex requests are significantly less likely to result in performances of euthanasia compared to non-complex requests **(Chapter 2)**. The complexity of a euthanasia request seems to be predominantly linked to assessing the substantive requirements (patient's eligibility for euthanasia), such as mental capacity, as revealed in our study in **Chapter 5**. More specifically, physicians find it particularly complex to assess the substantive requirements in patients being hospitalized, with heart failure, with a cerebrovascular accident, with age-related health issues, with dementia, with accumulated psychosocial and/or existential problems, and with psychiatric conditions.[15] The latter could partly explain why we found that euthanasia requests from patients with psychiatric conditions are less likely to result in performances of euthanasia compared with requests from patients with cancer **(Chapter 2)**. In fact, physicians consider euthanasia requests assessments from patients with cancer less complex.[15,16]

However, complexity goes beyond the assessment of substantive requirements. Physicians may also experience complexities on the day and during the act of performing euthanasia **(Chapter 5)**. For example, physicians may face medical-technical and psychosocial complexities, such as obtaining intravenous access and providing adequate psychosocial support to the patient's relatives **(Chapter 5**). These results are consistent with a recent scoping review, which found that medical-technical complexities during the performance include difficulties in obtaining or maintaining intravenous access (reported in about one-fifth of the studies included in the review), patients dying too slowly or not dying (in about one-third of the studies), and patients dying too quickly (in about one-tenth of the studies).[17]

In addition to these potential complexities in euthanasia practice, the findings of this dissertation also show that physicians can encounter various problems in their CDS practices. Firstly, physicians identify problems related to themselves and other physicians **(Chapters 6 and 7)**. For example, some physicians lack the required expertise to perform CDS (control through expertise frame), engage in CDS with incorrect intentions (strict due care frame), are reluctant and hesitant to perform CDS due to professional stigma, experience fear of making clinical errors in the performance of CDS, and face time constraints in monitoring the depth of the sedation (**Chapters 6 and 7).** The latter could explain why physicians in Belgium often opt for deeper sedation more quickly –thus administering it less proportionally as recommended by guidelines- compared to their counterparts in the United Kingdom (UK).[18] Many of the identified problems concerning physician practice resonate with prior research, particularly highlighting the assessment and monitoring of CDS as complex processes.[19,20] However, the professional stigma and the fear of making clinical errors are relatively novel findings. This can signify that CDS is not uniformly viewed as a normal medical practice among physicians. This contrasts previous studies in Belgium and the Netherlands, where physicians regarded CDS as a normal medical practice.[21–23] Secondly, physicians also note problems concerning relatives **(Chapters 6 and 7)**. For example, physicians report that relatives sometimes exert pressure on physicians to perform CDS in patients with severe loss of mental capacity (mainly those with severe dementia or in a vegetative state in ICU) to end their lives in dignity **(Chapter 6)**; and that relatives often hold misconceptions about the process of CDS **(Chapters 6 and 7)**. This reflects prior research on relatives' experiences, indicating that such problems predominantly stem from providing insufficient information to relatives and the distressing nature of being involved in CDS practice.[19,24,25] Thirdly, physicians experience problems concerning patients **(Chapter 6).** More specifically, patients nearing death often request CDS to have a 'peaceful' death and to avoid potential suffering **(Chapter 6)**. Certain physicians honor such requests, even when some indications for CDS are not fulfilled (safeguarding patient choice frame and facilitating dignity frame) **(Chapter 6)**. This is in keeping with the UNBIASED (UK, the Netherlands, Belgium International) Study, which revealed that physicians in Belgium emphasize prioritizing patient preferences, viewing CDS as a patient choice or a dynamic decision-making process in which patients can actively engage.[26–29] This is in contrast with physicians in the UK, who prioritize informing patients about the process and outcomes of CDS rather than granting them autonomy in choosing CDS.[26–29]

Although the previous sections have mainly addressed potential complexities and problems, we do not want to give the impression that they characterize all euthanasia and CDS practices. On the contrary, physicians and other HCPs across all our qualitative studies clearly state that problems and/or complexities occur in the minority of cases **(Chapters 4, 5, 6, and 7)**. They report experiencing personal and professional satisfaction from involvement in these practices, despite the inherent intensity of it. Moreover, they often perceive it as a privilege to guide patients throughout their euthanasia and CDS trajectories, especially those they have cared for over a long period prior to their euthanasia and CDS trajectories **(Chapters 5, 6, and 7)**. These findings align with other studies, highlighting the positive experiences of HCPs involved in euthanasia and CDS practices.[30–40] For example, HCPs in these studies have described rewarding feelings of being there for patients requesting euthanasia and relatives, personal growth, a sense of becoming a better HCP, and increased confidence.[40,41] This is also exemplified by the autoethnographic study by Beuthin, in which she described how her engagement in assisted dying practice connects her with ethical dimensions inaccessible through other professional means.[42]

Do we need a multi-solution and more integrated approach?

Thus, what considerations and/or questions can be raised in response to the various complexities and problems that may arise in practice?

Firstly, the variety of potential complexities and problems seems to imply the need for a variety of corresponding solutions (actions, control measures, or good practices) to counter these. Our findings in **Chapter 6** support this as physicians propose various solutions, actions, and control measures to improve CDS practice. Furthermore, this is also supported by our findings in **Chapter 5,** in which HCPs report deploying multiple good practices partly to address and anticipate (potential) complexities and problems in euthanasia practice. These findings suggest that there is no simple one-to-one relationship between a 'specific' problem (complexity or challenge) and a 'specific' solution (action, control measure, or good practice) in the context of euthanasia and CDS practices. In other words, our findings indicate that a combination of multiple solutions –i.e., a multi-solution approach- is more likely to effectively address one or multiple problems than relying on a single solution. Applied to the CDS practice, for example, our findings in **Chapters 5 and 6** indicate that improper assessments for CDS (‘the problem’) can be addressed through seeking expert advice or expert consultation, training attending physicians, implementing CDS registration, and deploying a shared decision-making process involving multiple professionals (‘the multiple solutions’). The suggestion of a multi-action approach supports current Theories of Quality improvement.[14,43,44] These models state that implementing various solutions (actions, control measures, or good practices) has a higher potential for improving the overall quality of practice, whereas focusing on a single solution (action, control measure, or good practice) leans more toward quality assurance, that is ensuring compliance with a predetermined standard or requirement.[43,44] Furthermore, deploying a multi-solution approach to tackle a certain problem is also in keeping with other theories and frameworks, such as ‘Complexity Theories’, ‘Collective Impact Frameworks’, ‘Systems Theories’, ‘Socio-Ecological Frameworks’, and current ‘Implementation Frameworks’.[45–50] Moreover, these theories and frameworks further suggest that an integrated approach may be necessary to effectively address a problem, meaning that the solutions must be aligned with each other (on multiple levels), partly to ensure higher effectiveness and efficiency.[45–50] This is also substantiated by our findings, for example, in **Chapters 6 and 7,** as physicians situate some solutions for CDS practice at either the micro, meso, or macro level. Importantly, this does not imply that we believe that a multi-solution and integrated approach is needed or warranted in all settings and/or contexts (such as in Flanders or Belgium), as this is impossible to claim based on the data gathered for this dissertation. Instead, our main message is that those facing one or multiple complexities and problems in their euthanasia and CDS practices -e.g., HCPs, group practices, hospitals, jurisdictions, etc.- should consider adopting such an approach as it can be more beneficial than relying on a one-solution approach.

Secondly, those seeking to address the problems and complexities in their CDS and euthanasia practices should also consider ascertaining the magnitude and frequency of specific complexities and problems before implementing appropriate solutions (actions, control measures, or good practices). This could be achieved, for example, by conducting quantitative studies with a cross-sectional or full-population design.

Thirdly, it is also essential to highlight that we identified solutions, actions, control measures, or good practices in our studies using HCPs’ lived experiences of their own euthanasia and CDS practices. It is not unlikely that some solutions (actions, control measures, or good practices) would not yield the desired outcomes in the practices of others. Therefore, we recommend examining their effectiveness further, for example, by conducting implementation and evaluation studies.

Fourthly, it is also important to consider the potential side effects of specific solutions (actions, control measures, or good practices) before implementation. For example, implementing mandatory peer consultation for CDS may result in substantial delays in actual performance following an extended period of unbearable suffering.[21]

2. How patients requesting euthanasia and their relatives view and experience euthanasia practice

Euthanasia as a multidimensional and dynamic process

This dissertation suggests that patients requesting euthanasia and their relatives rather experience euthanasia practice as a multidimensional and dynamic process, primarily characterized by physical-functional, psycho-existential, and social-relational dimensions (or dynamics), than as a unidimensional and linear process, solely characterized by a medical dimension (or dynamic) **(Chapter 4)**. This is substantiated by the multitude of support needs they may experience in their euthanasia trajectories **(Chapter 4)**, which we can categorize along the following dimensions:

- <u>Physical-functional dimension</u>, including, e.g., ‘support for maximizing daily functioning’ and ‘support for handling organizational and practical matters’;
- <u>Psycho-existential dimension</u>, including, e.g., ‘support for navigating existential questions’, ‘support for managing meaningful activities’, ‘support for psycho-emotional regulation’, and ‘support for understanding the process toward euthanasia’;
- <u>Social-relational dimension</u>, including, e.g., ‘support for facilitating social interaction’ and ‘support for making sense of the patient’s desire for euthanasia’.

Furthermore, most of the above-mentioned support needs mirror palliative and end-of-life care needs.[51–60] However, in contrast to these needs, we did not identify any spiritual support needs among patients requesting euthanasia and their relatives **(Chapter 4)**. Most likely, this can be attributed to patients and relatives not identifying themselves as being spiritual and/or religious, as research has shown that spiritual and religious beliefs are the main predictors of the presence of spiritual needs among patients at the end of life and their relatives.[61–63] Thus, patients requesting euthanasia and their relatives can be argued not to differ substantially from those in other end-of-life trajectories, particularly in terms of their support needs. For example, a patient with cancer in their euthanasia trajectory can be assumed to have similar support needs to a patient with cancer in a palliative care trajectory. This implies that HCPs can, to some extent, draw upon valuable insights from the support needs in other end-of-life trajectories to fulfill those in euthanasia trajectories. This is partly supported by our findings in **Chapter 5,** in which various good practices in euthanasia align with good practices recognized in palliative and end-of-life care, such as spiritual-existential support, bereavement care for relatives, assessing and meeting patient needs, and being a compassionate HCP.[64–66]

The importance of involving relatives

This dissertation highlights the importance of involving relatives in euthanasia practice. This is partly materialized in our finding that patients requesting euthanasia and their relatives have a strong desire for social connectedness and meaningful interactions with each other throughout the euthanasia trajectory **(Chapter 4)**. This confirms prior research on assisted dying in which patients and relatives value having strong and close bonds with each other, experiencing their assisted dying trajectories as processes of (inter)personal growth.[16,67–70] Nonetheless, patients and relatives acknowledge that their social interactions often come with particular obstacles and challenges throughout the euthanasia trajectory, such as interpersonal tensions and conflicts **(Chapter 4)**. This corroborates findings from Dees et al., who characterized euthanasia practice as a relational complexity, as the relationships between patients and relatives are susceptible to various difficulties, such as miscommunication, mutual coercion, and a failure to fully recognize the severity of the patient's unbearable suffering.[69] Due to these encountered obstacles and challenges, patients and relatives in our study in **Chapter 4** emphasize their need for support in facilitating social interactions. Despite potential interpersonal tensions and conflicts, involving relatives (as much as possible) throughout the euthanasia trajectory seems justified due to the plausible benefits for all parties involved. For patients, for example, having relatives close and involved can enhance their quality of life and death.[67] For relatives, for example, involvement can improve their bereavement outcomes and mitigate anticipatory grief,[71] which HCPs also underline in our study **in Chapter 5**. For HCPs, for example, it provides a way to gain a comprehensive understanding of the patient's unbearable suffering and to ascertain that the euthanasia request is not influenced by pressure from relatives **(Chapter 6)**.

Nevertheless, certain issues need to be considered when involving relatives. First, it is essential to obtain the patient's consent and asses their preferences regarding (the degree of) involvement. HCPs in our study in Chapter 5 consider this to be a good practice, as it safeguards patient autonomy. Second, it is also important to acknowledge that involving relatives should not be pursued unconditionally, especially when patients strongly oppose this. This is particularly relevant for patients with psychiatric conditions, as their relatives are sometimes playing a significant role in their suffering.[72] Hence, it is paramount for HCPs to understand the patient's motives behind such opposition and strive to involve relatives accordingly, for example, using separate or joint family conversations **(Chapter 5)**. In this respect, however, patients should never be coerced and always remain the central protagonists in their own euthanasia trajectories.

Is a partially demedicalized support approach the way forward?

As discussed in the General Introduction of this dissertation, medicalization refers to the societal process in which previously non-medical aspects of life –such as death and dying- are increasingly approached as medical issues, and thereby, mainly managed by medical professionals.[73–76] As a result, end-of-life trajectories have shifted from social and existential challenges to predominantly medical ones.[73,76] Following this, a euthanasia trajectory can be seen as a predominantly medicalized trajectory as it involves a 'chain' of medical-related aspects and actions, such as:

- the patient has to voice the euthanasia request to their attending physician;
- the attending physician has to assess the euthanasia request – e.g., by reviewing the medical file and examining the patient-;
- the physician has to ascertain that the patient has a medical condition without the prospect of improvement and that the suffering results from a severe and incurable condition caused by illness or accident;
- a second (and third) physician has to examine the patient;
- the physician has to administer the lethal medication.

Thus, it is not unlikely that euthanasia trajectories can be experienced as overly medicalized. In fact, this is partly evidenced by the findings in **Chapter 4,** in which relatives note that physicians often tend to explain the patient's unbearable suffering solely from a medical standpoint, describing it as a direct manifestation of the medical condition. That is why relatives require support to understand the patient's desire for euthanasia, as it enables them to comprehend the broader and holistic context of the suffering **(Chapter 4)**. Thus, this along with our findings that patients and relatives experience euthanasia as a multidimensional, dynamic process and that the involvement of relatives is important**,** suggest that a *partially* demedicalized support approach can benefit patients and relatives. With partial demedicalization, we emphasize that achieving a *complete* demedicalization is neither possible nor feasible, given the medical actions and procedures mandated by the legal requirements stipulated in the Belgian Act on Euthanasia (and other legal frameworks for assisted dying). This partially demedicalized support approach has also been recommended by other research scholars, who believe that non-medical professionals can take a more significant role in assisted dying practices, such as social workers, spiritual advisors, individuals familiar to the patients, and even the community.[77,78] Simultaneously, they have advocated for performing assisted dying as much as possible in demedicalized settings, such as home settings and palliative hospices.[77,78] In other words, we advise that HCPs strive for an optimal equilibrium between 1) a medical approach that is required by the legal requirements and the need for impeccable performance, and 2) a partially demedicalized support approach with physical-functional, psycho-existential, and social-relational components to fulfill the multidimensional needs of patients and their relatives. Specific forms of a partially demedicalized support approach may include, for example, having music played during the performance of euthanasia to create a serene atmosphere **(Chapter 5)**; or actively engaging as an HCP in farewell rituals to foster connection with the patient and their relatives while mitigating their perception of being ‘solely’ an HCP **(Chapter 5)**.

To conclude this paragraph, it may be worthwhile to *paraphrase* Allan Kellehear to effectively encapsulate the essence of these findings: ‘Dying *through euthanasia* is a social experience with a medical component, rather than a medical experience with a social component’.[79]

3. The spectrum of professional involvement as support practice: unity is strength?

This dissertation indicates that, in euthanasia and CDS practices, there exists a spectrum of professional involvement as support practice **(Chapters 2, 3, 5, 6, and 7)**. With professional involvement, we refer to involving *at least one additional HCP* (in addition to the attending physician) as a form of support in addition, and which goes beyond the assessing the legal requirements by a consultant in the case of euthanasia. This further suggests that professional involvement may hold substantial value, and in some cases, can be deemed as an essential precondition to ensure good practices, which physicians and other HCPs also state in our studies in **Chapters 5 and 6**.

In this section, we will discuss more in-depth the various manifestations of professional involvement we found as support practices in euthanasia and CDS. Additionally, we will elaborate upon the potential role of palliative care involvement in euthanasia practice, as our findings show its valuable contribution as additional support practice.

Professional involvement in CDS practices

Our studies in **Chapters 6 and 7** found that physicians assign a prominent role to professional involvement in CDS practice due to its added value. As such, some physicians view professional involvement as essential for improving CDS practice **(Chapter 6)**. Therefore, these physicians advocate for mandatory peer consultation, based on their reasoning that CDS practice could be substantially improved by consulting experts for the assessment of medical indications (control through expertise frame), and by involving multiple HCPs in a shared decision-making process to ensure strict adherence to medical indications for CDS (strict due care frame) **(Chapter 6)**. Consequently, physicians frequently deploy these forms of professional involvement in their own CDS practices **(Chapter 6)**.

These findings contradict those of Koper et al.[21] In their study, physicians viewed peer consultation as having limited added value, because of attending physicians having the necessary expertise, CDS being a normal medical practice, experienced time constraints, and concerns regarding potential conflicts between attending physicians and peer consultants.[21] Peer consulting and shared decision-making have been incorporated in several guidelines for CDS, and several research scholars have recommended using them to improve CDS practice.[80–82] Moreover, the European Association for Palliative Care (EAPC) recommended framework for palliative sedation has also emphasized the importance of interdisciplinary assessment of medical indications involving at least a palliative care physician or a palliative care team.[83,84] However, despite such emphasis on professional involvement, research has indicated that it only occurs in a small proportion of CDS cases. Studies in the Netherlands, for example, have shown that professional involvement through peer consultation occurs in less than one in five CDS cases.[85,86] In Belgium, on the other hand, Chambaere et al. found that a physician or nurse was consulted in about one out of two cases of ‘intensified alleviation of pain and symptoms’.[87] As this includes all forms of palliative sedation, the number of CDS cases is most likely lower.[87]

In practical terms, expecting these numbers to reach 100% is unrealistic, as this would require mandating mandatory professional involvement in all CDS performances. We should consider that CDS is frequently performed urgently in response to the sudden manifestation of unbearable suffering from refractory symptoms, implying that conducting peer consultations prior to performance is undesirable and unfeasible. However, in other cases, it is recommended to aim for professional involvement – e.g., through peer consultation-, as it can lead to a more accurate assessment of indications. This is evidenced by a study by Graeff et al., who found that in 41% of cases in which a palliative team was consulted for CDS, negative advice was voiced due to the availability of alternative treatments to treat the unbearable suffering.[88]

Professional involvement in euthanasia practices

Our findings indicate that the mandatory peer consultations for a euthanasia request assessment function as support practices (i.e., practices addressing the support needs of attending physicians) in addition to their functioning as control practices (i.e., practices merely to seek advice on the legal requirements). On the one hand, this is substantiated in our finding that about one out of three attending physicians pose additional questions to LEIF consultants, for example, regarding the overall legal procedure and practical issues related to performance **(Chapter 2)**. This reflects a systematic review by Kono et al., demonstrating that attending physicians across all permissive jurisdictions have inquiries regarding the legal procedure as it leaves room for interpretation, being ambiguous and confusing.[89] The questions about practical issues, on the other hand, may arise from the fact that attending physicians are not often engaged in euthanasia practices.[90] Additionally, peer consultation functioning as support practice is also substantiated in our findings that some attending physicians request LEIF consultants to assist in performing euthanasia (26%), and to carry out the performance of euthanasia (15%) **(Chapter 2)**. These findings are consistent with a previous study conducted in Belgium, which reported that consultants assisted in one-third of the performances of euthanasia following consultations.[91] Accordingly, our studies revealed that the majority of LEIF consultants had been present during at least one performance of euthanasia in the year prior to our survey **(Chapter 3);** and that about one-fifth of attending physicians had not carried out the performances of euthanasia following the peer consultations, but had been carried out by other physicians (mainly LEIF consultants) **(Chapter 2)**. Taken together, the peer consultation practice in the context of euthanasia seems to function as a ‘Swiss army knife’, namely, as a tool accommodating the specific needs of attending physicians. For example, during peer consultations, attending physicians can seek guidance on how to communicate with relatives, support patients after rejecting their requests, and complete the registration form **(Chapter 5)**. While this support function is highly valuable –and potentially acts as an additional safeguard-, it is imperative to ensure that it does not overshadow the control function of legal compliance, which safeguards the patient. Therefore, it is essential for the LEIF organization to explicitly emphasize the control function in their training of LEIF consultants. Moreover, the organization should stress refraining from taking over performances of euthanasia unless there are valid reasons, such as stepping in if the attending physician feels mentally unprepared to perform euthanasia on the scheduled day.

These findings of involving other physicians in the performance of euthanasia (i.e., multi-professional collaboration) suggest that some attending physicians have the intrinsic need to avoid performing euthanasia alone. This appears logical for several reasons. First, professional involvement during the performance -e.g., through attendance- can enhance attending physicians' self-efficacy in carrying out the actual act of performance, thus empowering them.[92,93] Physician empowerment holds particular relevance given the ethical weight involved in performing euthanasia. Second, involving other HCPs can also be seen as a way of professional preparedness to anticipate potential hazards and risks, which has been identified as a good practice in our study in **Chapter 5**.

In addition, we also found that multidisciplinary collaboration functions as a support practice, therefore being deployed as a good practice by HCPs **(Chapter 5)**. More specifically, multidisciplinary collaboration is mainly deployed for two purposes: 1) assessing euthanasia requests, and 2) supporting patients and relatives in their euthanasia trajectories **(Chapter 5)**. Attending physicians in our study in **Chapter 5** explain that they rely on multidisciplinary collaboration for these purposes in order to leverage specific expertise they lack. For example, social workers and case managers are involved in assisting patients with the administrative tasks regarding the euthanasia procedure, nurses in obtaining intravenous access for the administration of the lethal drugs, and psychologists in providing bereavement care to relatives following the performance of euthanasia **(Chapter 5)**. Previous studies in other permissive jurisdictions have also noted the utilization of multidisciplinary collaborations to support patients, relatives, and attending physicians in assisted dying practices, while describing the important roles of professionals from different disciplines, including

- nurses,
- social workers,
- palliative care professionals and consultants,
- case managers,
- psychologists and mental health professionals,
- pharmacists, rehabilitation therapists,
- chaplains,
- ethicists,

- clinical managers,
- respiratory therapists,
- spiritual workers,
- occupational therapists.[17,33,37,41,94–99]

Moreover, HCPs in Canada have also identified multidisciplinary collaboration as a facilitator to providing high-quality care in assisted dying practice.[37] Furthermore, several Flemish guidelines for euthanasia have endorsed multidisciplinary collaboration as recommended practice or and additional safeguard.[100,101]

Palliative care involvement can take up a pivotal role in euthanasia practices

Hence, professional involvement has taken up an important role in euthanasia and CDS practices, with HCPs acknowledging its added value to meet personal and practice needs. Following that, this dissertation also presents evidence that palliative care involvement can offer additional benefits in the context of euthanasia practice **(Chapters 4 and 5)**. Here, we will elaborate upon that.

Firstly, as discussed above, patients requesting euthanasia and their relatives experience multidimensional support needs along physical-functional, psycho-existential, and social-relations dimensions that are similar to palliative care needs **(Chapter 4)**. Hence, palliative HCPs can be argued to be well-positioned to effectively address their support needs, considering that intervention studies have demonstrated their extensive knowledge and preparedness to meet multidimensional support needs.[102,103]

Secondly, in our study on good practice in euthanasia **(Chapter 5)**, we identified a) several overarching good practices that closely align with the principles of a palliative care approach, and b) several specific good practices that intersect with the particular expertise of palliative HCPs; such as

- patient-centeredness including, e.g., assessing and meeting needs, psychosocial support, and spiritual-existential support. Patient-centeredness is recognized as a prominent principle in palliative care, emphasizing, for instance, the patient's central role in decision-making and care planning.[104]
- family-centeredness, including, e.g., involving relatives, grief and bereavement care-; facilitating communication between patients and relatives. A family-centered approach is considered an essential element in palliative care, recognizing the importance of involving and supporting the patient's relatives.[105]

- compassionate, proactive, and communicative HCPs. These professional attributes are widely observed among palliative care providers and receive substantial attention in palliative care training programs.[106–108]

Thirdly, as mentioned previously, attending physicians and other HCPs endorse professional involvement in euthanasia practice, mainly through multi-professional and multidisciplinary collaborations **(Chapter 5)**. This resonates with the holistic and multidisciplinary approach to palliative care, which emphasizes collaborative efforts among professionals from diverse disciplines, including medicine, nursing, social work, psychology, and others.[109] Additionally, attending physicians highlight deploying these collaborations to leverage their expertise in assessing substantive requirements, among other reasons **(Chapter 5).** In this context, for example, collaborating with palliative care professionals appears particularly valuable given their extensive expertise in assessing and addressing unbearable suffering (substantive requirements in nearly all jurisdictions), e.g., in CDS cases.

From a practice perspective, based on these three evidence-based arguments, we claim that euthanasia and palliative care should not be viewed as opposing practices, but as complementary ones.[110] Thus, the Belgian model, which integrates both practices (‘integral palliative care’) seems empirically justified as this integration most likely provides better support for patients requesting euthanasia, their relatives, and attending physicians.[110,111] This is supported by Belgian physicians and nurses, who consider euthanasia being part of comprehensive end-of-life care.[112,113] Nonetheless, the international debate on such integration remains contentious, with calls for palliative care to distance itself from euthanasia practice.[114] For example, the EAPC stated in their 2016 White Paper that assisted dying should not be included in palliative care, despite the varying opinions of the palliative care experts included in the study for this paper.[115] However, we encourage palliative care organizations and associations in jurisdictions with assisted dying legislation to consider our findings in their discussions and deliberations on the integration of euthanasia practice into their palliative care services, particularly if they are committed to conducting an evidence-based –and intellectually honest- debate.

However, it is important to clarify that we are not advocating for implementing a standard ‘palliative filter’- i.e., the mandatory provision of palliative care prior to performing euthanasia and requiring the involvement of palliative care professionals in assessing euthanasia requests-, as some Belgian research scholars have recommended.[116–118] It can be argued that patients requesting euthanasia and receiving euthanasia may not always benefit from such a standard palliative filter.[119] This is supported by findings from Dierickx et al., showing that in over half of all euthanasia cases in Belgium, patients were not referred to palliative HCPs because their palliative and supportive needs had already been adequately addressed.[120]

4. The potential psychological strains and burdens among HCPs

Despite the numerous positive experiences reported by physicians and other HCPs across our qualitative studies (as mentioned previously), this dissertation also shows that professional involvement in euthanasia and CDS practices can be accompanied by psychological strains and burdens among HCPs **(Chapters 5, 6, and 7)**.

In the context of euthanasia practice, physicians and other HCPs in our study in **Chapter 5** explicitly acknowledge that involvement can have a negative impact on their psychological well-being. They also note this psychological impact on their colleagues **(Chapter 5)**. These findings are consistent with systematic reviews.[41,121] In contrast to these systematic reviews,[41,121] our study did not find a psychological strain among HCPs due to feelings of discomfort when discussing euthanasia-related topics. This may be attributed to physicians' familiarity with euthanasia practice because of its long-standing implementation in Belgium. In general, a psychological impact among HCPs appears to stem from the moral dilemma and weight associated with the decision-making and performance of euthanasia.[97] Decision-making regarding euthanasia may be one the most profound moral dilemmas in healthcare practice as it seemingly and paradoxically involves ending a person's life. Additionally, HCPs involved in palliative and end-of-life care can experience negative psychological impacts as well, with about one out of four HCPs reporting reduced psychological well-being.[122,123]

In the context of CDs practice, some physicians in our studies **(Chapters 6 and 7)** report experiencing

- pressure from some relatives to perform CDS to hasten death in patients with severe mental impairment, particularly in those with advanced dementia or with minimal consciousness resulting from irreversible brain damage in ICUs;
- personal pressure at times to administer higher doses of sedation due to time constraints and a lack of professional support in monitoring the depth of sedation**;**
- coercion from colleagues in team settings sometimes to not perform CDS, despite their personal beliefs of being the appropriate decision;
- coercion from their professional teams and/or institution not to perform CDS due to moral reservations;

- frustrations about the absence of a comprehensive legal framework covering all medical end-of-life decisions in Belgium;
- fears of making clinical errors in relation to CDS.

Most of these findings correspond to prior research on the impact of being engaged in CDS practice, which found that CDS-related burden among HCPs is linked with experiencing difficulties in diagnosing refractory symptoms, performing CDS as life-shortening decisions, managing conflicting wishes between patients and relatives, experiencing disagreements within the professional team, lacking sufficient skills, and having inadequate coping strategies.[124,125]

Thus, how can HCPs effectively manage and anticipate psychological strains and burdens in euthanasia and CDS practices? In our study in **Chapter 5**, HCPs explain that they deploy two good practices for this in euthanasia practice. The first good practice involves prioritizing self-care, such as setting moral boundaries and engaging in relaxing activities **(Chapter 5)**. This finding aligns with previous research conducted among nurses in euthanasia practice in Flanders, who favored debriefings with a psychologist as a form of self-care.[113] The second good practice involves paying attention to the psychological well-being of colleagues **(Chapter 5)**. This includes serving as a supportive companion and/or confidant for colleagues and organizing debriefing sessions for open discussions and emotional support. Most likely, these identified good practices can also be applied in CDS practices to mitigate and/or anticipate the potential negative psychological impact of professional involvement. An additional promising approach to mitigating psychological impact involves special training to improve personal resilience, which has demonstrated effectiveness among palliative care physicians.[123]

Notably, HCPs in our study **(Chapter 5)** and those in previous research in other countries,[41,121,124,125] have pointed out the lack of established support structures that they can turn to when experiencing negative psychological strains and/or burdens in euthanasia and CDS practices. HCPs seemingly need to rely on their self-awareness and the altruism of others to safeguard their psychological well-being. Therefore, we recommend implementing support structures across organization levels that provide HCPs with the necessary psychological support when needed. In the context of Flanders and Brussels, a possibility could be that the LEIF organization offers such support, given its expertise and wide recognition among HCPs involved in euthanasia and CDS practices.

Implications and recommendations for practice, policy, and research

In the following sections, we will articulate several implications and recommendations for practice, policy, and research, based on the findings of this dissertation.

1. Implications and recommendations for practice and policy

Adopt a well-coordinated and proactive support model for patients and their relatives throughout their euthanasia trajectories, incorporating a patient-and-family-centered, partially demedicalized, and multidimensional approach

First of all, following our study findings, we propose adopting patient-and-family-centered support for patients and their relatives throughout their euthanasia trajectories. This involves assessing and meeting their diverse needs, preferences, and values, as our findings indicate that this can enhance their quality of life (and death) and their euthanasia experiences in general. We recommend continuous assessment as their needs, preferences, and values may change throughout the euthanasia trajectory.

Furthermore, we advise involving relatives from the beginning of the euthanasia trajectory after evaluating the patient's opinion on this and obtaining their consent. In case of strong opposition towards involvement, it is advisable to examine the underlying motives behind the patient's resistance, mainly to ensure that relatives are not exerting any pressure on them to hasten death. The early involvement of relatives is particularly important for mitigating (potential) anticipatory grief and the bereavement process, rather than limiting their involvement to the day of the performance. Similarly, attention should be given to their role as family caregivers. Our findings in Chapter 4 show that relatives require support facilitating this role, as being a family caregiver holds great significance and provides a sense of meaning during the final moments with their loved ones. The psycho-emotional needs of relatives should also be recognized as they might experience some burden due to neglecting their own feelings and emotions throughout the euthanasia trajectory. HCPs should also bear in mind that the support should be extended beyond the (day of) performance for certain relatives, e.g., those with indications of complicated grief disorder prior to the performance. For them, it can be valuable to provide needs-based, follow-up support, such as grief counseling sessions. During this follow-up, relatives can be further referred to specialized support services if needed. Health policy could facilitate follow-up support by, for example, mandating at least one free follow-up session after the performance of euthanasia, conducted by a palliative HCP.

Secondly, we recommend deploying a partially demedicalized and multidimensional support model for patients and relatives, as we have previously argued in this dissertation. This entails focusing on the social-relational, psychological-emotional, existential, and physical-functional aspects of the euthanasia trajectory. With a partially demedicalized approach, we do not propose reducing the involvement of HCPs throughout the euthanasia trajectory, but suggest minimizing the medical emphasis in interactions and communication with patients and relatives (if feasible). Examples of such partially demedicalized approach include physicians refraining from wearing white coats during the performance of euthanasia, using less medical jargon, adopting a holistic approach when assessing the unbearable suffering, and avoiding the preparation of the lethal drugs in the presence of patients and their relatives (Chapter 5).

Thirdly, we recommend applying a well-coordinated and proactive support model. With ‘well-coordinated’ support, we mean ensuring a fluent euthanasia trajectory, as our findings show that the involvement of different HCPs can sometimes lead to fragmented support and unnecessary complexity (Chapter 5). For example, case managers and support navigators could play a valuable role in this. Moreover, in the context of Belgium, we advise attending physicians to comply with the mandatory referral requirement (stipulated in the euthanasia legislation if they choose not to assess the euthanasia request) by providing patients with clear instructions for alternative physicians and healthcare centers while continuing patient follow-up. Our study in Chapter 5 suggests that this might contribute to the continuity of the euthanasia trajectory. With ‘proactive’ support, we mean providing (light forms of) support to patients and relatives prior to the manifestation of potential problems and difficulties. This proactive approach also includes managing the expectations of patients and relatives, which HCPs deploy as a good practice (Chapter 5). This involves anticipating common misconceptions about euthanasia. In this respect, it can be valuable to highlight from the start of the euthanasia trajectory that euthanasia is not a patient right and that the request may be denied.

Following this, we endorse the development of evidence-based euthanasia guidelines for attending physicians and other HCPs on how to support patients requesting euthanasia and their relatives throughout their euthanasia trajectories using a patient-and-family-centered, partially demedicalized, and multidimensional approach. This is especially relevant in the context of Belgium, where existing euthanasia guidelines have paid limited attention to the support for patients and relatives throughout their euthanasia trajectories.[101]

Apply and facilitate multi-professional, multidisciplinary, and palliative care involvement

We recommend that attending physicians and other HCPs actively embrace and engage in multi-professional and multidisciplinary collaborations in euthanasia practices. Our findings have shown that this is particularly relevant in cases where complexities, problems, and challenges arise. According to our findings, these collaborations can improve euthanasia practice, such as request assessments, performances, and support for patients and relatives. Additionally, it can alleviate time constraints experienced by attending physicians while fostering their confidence and empowerment in terms of performance. Moreover, collaborating with palliative HCPs can yield substantial benefits due to their specific expertise in addressing the social-relational, psychological-emotional, existential, and physical-functional needs at the end of life.

In CDS practices, we also advocate for maximizing multi-professional, multidisciplinary, and palliative care collaborations, and for cultivating peer consultations as much as possible. Moreover, it is important to facilitate these peer consultations by organizing them in a low-barrier and accessible manner, for example, by minimizing the administrative burden for attending physicians. Ideally, these peer consultations should be supported by a shared decision-making process, as this can improve the assessment of medical indications and allows for exploring potential alternative treatment options. Additionally, we advise involving multiple HCPs in monitoring the depth of sedation, especially in the home setting.

Prioritize clear information, effective communication, and managing expectations as ways of patient and family empowerment

We advise HCPs to prioritize patient and family empowerment in euthanasia practice, that is enabling patients and relatives to exert influence and control over aspects of their euthanasia trajectories they deem important. This could be partly achieved by applying patient-and-family-centeredness (which we have discussed earlier), as this is considered a prerequisite of patient and family empowerment.[126] Furthermore, our studies have identified additional attributes of empowerment. Firstly, we recommend that HCPs safeguard patient autonomy, which entails maximizing the freedom of choice for patients regarding the course of the euthanasia trajectory. For example, this involves allowing patients to determine the date and time of the performance or seeking their consent regarding the extent of family involvement. Secondly, another attribute of patient and family empowerment includes managing the expectations of patients and relatives. On the one hand, this involves developing ‘euthanasia literacy’ and ‘euthanasia preparedness’ among patients and their relatives, which HCPs deploy as good practices (Chapter 5). On the other hand, this also involves providing patients and relatives with clear information and adequate knowledge about the euthanasia trajectory and ensuring thorough preparation for the actual performance. Thirdly, empowerment also entails making clear arrangements with patients and their relatives, so that they know what to expect, allowing them to actively engage in these arrangements. By managing their expectations, patients and relatives can make informed decisions and nurture their euthanasia trajectories with a comprehensive understanding of the practice. In line with this, we recommend clear and effective communication of all information to patients and relatives, using unambiguous language to prevent potential misconceptions.

Based on our collected data, we cannot provide a well-grounded, evidence-based recommendation for addressing situations in which patients' and relatives' needs conflict or relatives strongly oppose euthanasia. However, it can be warranted to prioritize maintaining serenity in these situations, which physicians identify and deploy as a good practice (Chapter 5). In some cases, this can even imply limited or no involvement of relatives. However, we recommend mediating social conflicts first, for example, by conducting separate or joint family conversations, as these might improve the sense of social connectedness between patients and relatives (Chapters 5 and 6).

Furthermore, we also recommend managing the expectations of relatives in CDS practice, particularly by clarifying the potential duration of CDS prior to its initiation. This proactive communication can help prevent pressure from relatives on physicians to hasten the dying process.

Prioritize medical-technical and interpersonal knowledge and skills among attending physicians

Our studies emphasize the importance of medical-technical and interpersonal knowledge and skills among attending physicians for ensuring high-quality euthanasia and CDS practices. Therefore, we propose that attending physicians prioritize the development of these skills and knowledge if they are involved in these practices. Interpersonal knowledge and skills –i.e., abilities and qualities to interact, communicate, and build relationships with other-[127] are deemed essential by HCPs in our studies for interacting with patients, relatives, and other HCPs. On the other hand, medical-technical knowledge and skills are seen as imperative for proper assessments and performances of euthanasia and CDS.

Additionally, we advise that the basic curriculum and postgraduate training for physicians pay attention to these forms of knowledge and skills, especially for those who frequently engage with patients at the end of life, such as general practitioners, oncologists, geriatricians, etc. We further recommend providing continuous training to refine such knowledge and skills, considering the evolving practice needs of attending physicians.

Also, our studies highlight the didactic value of bedside teaching (i.e., hands-on learning in a real-life setting) for physicians involved in euthanasia and CDS practices to develop skills, as they will not be frequently engaged in these practices. Therefore, we advise incorporating bedside teaching into courses focusing on euthanasia and CDS practices.

Establish a shared and precise definition of CDS (practice)

Our studies demonstrate that divergent definitions of CDS practice exist in medical and policy settings, including, for example, different medical indications and intentions. This variation in definitions (or lack of shared consensus on a precise definition) appears to yield confusion and conflicts among HCPs. Consequently, further clarification of what qualifies as CDS (practice) is warranted. As such, we support Morita et al. and Rady et al., [128,129], who have advocated for developing a uniform definition of CDs. It would also be beneficial to determine whether CDS can be a patient choice and under which medical indications, as many conflicts and disagreements stem from this issue. We recommend establishing a shared and precise definition of CDS practice involving all relevant stakeholders, including the medical field, health policy, patients, and their relatives.

In this respect, it may be advisable to explore establishing a legal framework in Belgium to define CDS and clarify its legal status, similar to the Claeys-Leonetti law in France that allows patients at the end of life to opt for CDS under certain conditions. However, establishing such a framework would also require careful consideration of its potential impact on other end-of-life practices, particularly euthanasia practice. There is a possibility that CDS may no longer be perceived as a normal medical practice following legislation, resulting in hesitancy among physicians to perform it. On the other hand, it is also possible that physicians may feel empowered by legal regulation to perform CDS. Alternatively, another approach could be to consider establishing a comprehensive legal framework encompassing all end-of-life practices, as physicians in our study in Chapter 6 also suggest. This need for a comprehensive legal framework is particularly evident in certain end-of-life trajectories of patients with severe loss of mental capacity, such as those with advanced dementia or in a vegetative state or coma. Our findings in Chapters 5 and 6 indicate that some physicians perform CDS to hasten death in these patient groups because of pressure from their relatives, partly because of the lack of a legal framework establishing death with dignity for these patient groups (‘facilitating dignity frame’).

Another potential avenue to provide clarity lies in the Belgian Order of Physicians (a legally mandated entity) issuing an authoritative pronouncement regarding the definition and modalities of CDS practice.

Monitor trends in end-of-life practices to inform evidence-based policies

Our study focusing on changes over time (Chapter 3) clearly demonstrates the importance of examining trends in euthanasia practice over time. Following this, we highly recommend that all permissive jurisdictions conduct population-level monitoring research programs to better understand the decision-making and implementation of end-of-life practices. These studies can provide the needed empirical insights for developing evidence-based policies and informing societal debates regarding end-of-life practices. Such insights can also be used, for example, to determine adherence to legal requirements, identify shifts in patient groups, uncover life-shortening practices without consent, and reveal regional variations. Therefore, we advise implementing structured monitoring research program for end-of-life practices in Belgium, following the example set by the Netherlands, where a population-level monitoring research program on end-of-life practices is mandated by legislation.

2. Implications and recommendations for research

Better understanding of how physicians make decisions regarding euthanasia and CDS

Our findings have shown that various personal, interpersonal, and environmental factors can influence euthanasia and CDS practices. However, physicians’ agency regarding decision-making of euthanasia and CDS remains under-researched hitherto. Agency refers to an individual's capacity to make decisions and exhibit specific behaviors within the interplay and constraints of their contexts.[130] Therefore, it would be interesting to examine physicians’ agency in euthanasia and CDS practices to understand better what exactly drives them to perform these practices. This can be accomplished by conducting ethnographic studies using actor-centered frameworks, such as structuration theory, to explore how rationality, power, and intentions (which are attributes of agency) are being constructed between physicians and other stakeholders –e.g., patients, relatives, and other HCPs.[131,132]

Need for more research with patients requesting euthanasia as research participants

Our study in Chapter 4 has been one of the few worldwide that has included patients requesting euthanasia as research participants. Hence, this patient group is highly underrepresented in the current literature. Our understanding of patients requesting and receiving euthanasia has mainly been derived from studies using second-hand accounts, for example, their HCPs and relatives. These studies have a higher potential for bias than those using primary accounts. Consequently, we strongly recommend conducting research involving patients requesting euthanasia as research participants. As such, we align with Zhang et al., who have called for paying more attention to the 'epistemic asset of personal experience' of patients requesting euthanasia through research to inform medical practice and health policy.[133] It could be interesting to conduct a qualitative longitudinal interview study using a narrative or phenomenological approach to explore how patients construct and attribute meaning to their euthanasia wish and how this evolves throughout the euthanasia trajectory. Our study in Chapter 4, along with previous research, indicates that a euthanasia wish follows a transformative process influenced by a complex interplay of social-relational, psychological-emotional, and existential-spiritual dynamics.[72,134,135]

Moreover, our study in Chapter 4 demonstrates that including patients requesting euthanasia in research is achievable and should not be dismissed as impractical or impossible. Throughout the semi-structured interviews, patients have consistently emphasized the value of research participation and of sharing their experiences regarding euthanasia practice. Similarly, Verhofstadt et al. found that adults with a euthanasia wish (and psychiatric conditions) experienced research participation as meaningful.[72,135] These findings show that including patients can lead to positive experiences and should not be avoided due to concerns about potential adverse impacts. In this regard, it is advisable for researchers to rather prioritize minimizing the impact of research participation on patients, for example, by exploring alternative research methods, such as a qualitative questionnaire that we used in our study in Chapter 4.

Further understanding of good practices in euthanasia

This dissertation found 28 good practices that HCPs deploy and identify in euthanasia practice based on their lived experiences. This represents merely an initial step towards fully elucidating the methods, actions, and approaches leading to better outcomes in practice. It is advisable to examine the actual impact of these identified good practices, for example, from the experiences of patients and their relatives. As such, we can determine their outcomes more effectively. Implementation, evaluation, and intervention studies are recommended to assess the effects of specific good practices. For example, a clusterrandomized controlled trial could study the effect of a family-centered approach in euthanasia practice on the quality of life and/or grieving reactions of the patient's relatives. For patients, for example, it can be worthwhile to study the effects of good practices using propensity score matching methods, as it may be ethically inappropriate to randomize them.[136] Moreover, it would be interesting to develop quality indicators for euthanasia based on the insights from the identified good practices. These indicators may allow us to measure and evaluate the quality of euthanasia practice, and facilitates comparing euthanasia practices across various settings, contexts, and jurisdictions.

Better understanding of the support trajectories of patients requesting euthanasia

Our study in Chapter 4 only provides a glimpse into the complex reality of the support needs of patients requesting euthanasia. It would be valuable to deepen further our understanding of their support needs and their support trajectories. More specifically, we lack insights into the forms and extent of support that patients receive prior to their euthanasia wishes, and how the (non-)uptake of this support influences their euthanasia wishes. Thus, an interesting study would be to investigate healthcare utilization patterns of patients requesting euthanasia using a full-population, administrative data approach.

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ENGLISH AND DUTCH SUMMARIES

English summary

General introduction

In recent decades, assisted dying and continuous deep sedation until death (CDS) have become increasingly important medical practices at the end of life. Assisted dying refer to practices in which lethal drugs are intentionally used to hasten the patient's death at the explicit and voluntary request of the patient. This practice includes euthanasia and physician-assisted suicide. In euthanasia, another person than the patient, most often a physician, administers the lethal drugs to end the patient's life at the voluntary and explicit request of the patient. In physician-assisted suicide, the physician provides or prescribes lethal drugs to a patient at their voluntary and explicit request, who subsequently self-administers these drugs to end their own life. Continuous deep sedation (CDS) is a form of palliative sedation. It involves the practice in which sedative drugs are intentionally administered, resulting in a continuous reduction of a patient's consciousness until death in order to alleviate the unbearable suffering from refractory symptoms. These medical end-of-life decisions and practices play an important role at the end of life. In Belgium, for example, it has been estimated that about 13% of all deaths are preceded by CDS, and 3% by euthanasia.

However, empirical research has shown that patients, relatives, and healthcare professionals (HCPs) involved may encounter various difficulties and challenges in these practices. These difficulties and challenges are believed to be partly linked to the control and support mechanisms within these medical practices. As a result, there is a growing consensus that both euthanasia and CDS would benefit from a better understanding of their control and support practices to address their potential for improvement. These issues have prompted the two main aims of this dissertation: 1) to describe current practices of control and support in euthanasia and to explore their potential for improvement in Flanders and Brussels, Belgium; and 2) to describe current practices of control and support in CDS and to explore their potential for improvement in Belgium.

Research questions

To address these two aims, this dissertation aims to answer the following research questions:

1. What are the characteristics and outcomes of peer consultations for a euthanasia request assessment, as reported by attending physicians? **(Chapter 2)**
2. What are the influences of these characteristics and outcomes of peer consultations on the performance of euthanasia, as reported by attending physicians? **(Chapter 2)**
3. What are the (quality) characteristics of peer consultations for euthanasia request assessments, and changes over time in these characteristics, reported by trained euthanasia Life End Information (LEIF) consultants? **(Chapter 3)**
4. What support needs do patients requesting euthanasia and their relatives experience throughout their euthanasia trajectories? **(Chapter 4)**
5. Which good practices do healthcare professionals deploy in euthanasia practice? **(Chapter 5)**
6. How do physicians frame control measures for continuous deep sedation until death? **(Chapter 6)**
7. What are physicians' experiences and perceptions of environmental factors affecting their practices of continuous deep sedation until death? **(Chapter 7)**

Methods

We conducted four studies to answer the aforementioned research questions of this dissertation. These studies reflect four different data collections using either a quantitative or qualitative research design. A quantitative research design was used to address research questions 1 and 2, while a qualitative research design was used to address research questions 3, 4, 5, and 6. In the studies on euthanasia (first dissertation aim), we studied data from Flanders and Brussels, the Dutch-speaking part of Belgium. In the studies on CDS (second dissertation aim), we studied data from Belgium.

Life End Information Forum Study

To address the first research question of this dissertation, we performed a cross-sectional survey study in Flanders and Brussel, Belgium, among attending physicians who 1) assessed a euthanasia request in the year prior to the survey, and 2) consulted with a LEIF consultant as the legally required second or third physician to obtain their advice on the patient's eligibility for euthanasia. Data were collected from

September 2019 to May 2020. To examine the characteristics of the peer consultations, we performed descriptive analyses. To examine the influence of these characteristics on the performance of euthanasia, we performed univariable logistic regression analyses.

To address the second research question of this dissertation, we conducted repeated cross-sectional survey studies among LEIF consultants in Flanders and Brussels, Belgium. In the first survey study, data were collected from May to September 2008. In the second survey study, we collected data from September 2019 to May 2020. We carried out descriptive analyses to examine peer consultations' (quality) characteristics for euthanasia request assessments. To identify changes in these characteristics over time (between 2008 and 2019), we performed Fisher's exact tests (2×2 table), Fisher-Freeman-Halton exact tests (2×3 table), and Pearson $\chi 2$ tests.

Support Needs Study

To answer the third research question of this dissertation, we conducted an explorative, qualitative study in Flanders and Brussels, Belgium, using 1) semi-structured interviews with patients requesting euthanasia and their relatives, and 2) personally written narratives of patients requesting euthanasia through qualitative questionnaires. Between December 2021 and September 2022, we collected the data. As concerns the data analysis, we deployed a multi-phased interpretative thematic approach.

Good Practices Study

To answer the fourth research question of this dissertation, we conducted a multimethod qualitative study using semi-structured interviews, focus groups, and an expert panel with HCPs engaged in euthanasia practice in Flanders and Brussels, Belgium. Between January and September 2022, we collected the data. Following this, we performed an interpretative thematic analysis in several phases.

Continuous Deep Sedation Until Death Study

To address the fifth research question of this dissertation, we performed an explorative, qualitative interview study with physicians having lived experience with the CDS practice in Belgium. We conducted semi-structured interviews with recruited physicians from February to May 2019. Following this, we performed a qualitative framing analysis. To address the sixth research question of this dissertation, we performed a secondary qualitative analysis of the data from the semi-structured interviews.

Dissertation findings

Chapter 2

Our findings revealed that the vast majority of attending physicians were general practitioners (92%). Among the consultations for a euthanasia request assessment, more than half involved patients diagnosed with cancer (57%), while 66% of patients were aged 70 years or older. The reasons most often cited by patients for requesting euthanasia were suffering without the prospect of improvement (49%), loss of dignity (11%), pain (9%), and tiredness of life (9%). In the vast majority of consultations (85%), attending physicians consulted the LEIF consultant due to their expertise. In nearly half of the consultations (46%), they consulted the LEIF consultant because of their independence (a legal requirement). In 91% of consultations, the consultants provided positive advice, i.e., the patient met the substantive requirements. Euthanasia was carried out in eight out of ten consultations (80%). We found that the likelihood of euthanasia being performed was higher in consultations in which loss of dignity, loss of independence in daily living, or general weakness or tiredness were reasons for requesting euthanasia, as compared to consultations in which these reasons were not reported. Moreover, consultations involving patients with a psychiatric disorder were found to be less likely to result in the performance of euthanasia, compared to consultations involving patients with cancer.

Chapter 3

In 2019, compared to 2008, there was a significant increase in the proportion of LEIF consultants who were below the age of 40 years (25% in 2019 vs. 10% in 2008, p=0.006) and those who were at least 60 years old (34% in 2019 vs. 20% in 2008, p=0.006). As for their activities related to assessing euthanasia requests over 12 months, we found a significant decrease in the proportion of patients who did not meet the substantive requirements for euthanasia in 2019 compared to 2008 (42% in 2019 vs. 60% in 2008, p=0.020). In their most recent euthanasia request assessments, LEIF consultants conducted significantly more assessments for patients aged 80 years or older than in 2008 (31% in 2019 vs. 9% in 2008, p<0.002). Conversely, there was a significant decrease in the proportion of assessments for patients with cancer (53% in 2019 vs. 70% in 2008, p=0.034). As for adhering to quality criteria for consultation in their most recent assessments, LEIF consultants in 2019 dealt with the following topics significantly more often than in 2008: unbearable suffering (87% in 2019 vs. 65% in 2008, p=0.003) and alternative treatments, including palliative care (48% in 2019 vs. 13% in 2008, p<0.001), and curative treatments (28% in 2019 vs. 5% in 2008, p=0.002).

Chapter 4

In total, we identified eight types of support needs. First, patients needed support for maximizing daily functioning, such as aid with transportation. This support was seen as vital for maintaining their self-worth and enabling them to remain independent at home in order to receive euthanasia. Second, relatives needed support in understanding the patient’s desire for euthanasia. This support was seen as a way to facilitate closure, accept the patient’s desire for euthanasia, and evaluate their own role in alleviating the suffering. Third, participants needed support for managing meaningful activities to maximize their remaining time together and give purpose to their euthanasia trajectories, for example, support for organizing a farewell ritual. Fourth, participants needed support for navigating existential questions, as these questions could lead to feelings of loneliness and distress. Fifth, participants needed support for psycho-emotional regulation, as their euthanasia trajectories are often characterized by intense and fluctuating emotions, such as anxiety, distress, and fear. Sixth, participants needed support for facilitating social interaction. Participants required this support to resolve social conflicts, improve social bounds, enhance communication with loved ones, and facilitate family engagement. Seventh, participants needed support for understanding the process toward euthanasia. This support would provide them with a better comprehension of the euthanasia legislation and procedure, and of the attending physician’s decision-making regarding euthanasia. Eighth, participants needed support for handling organizational and practical matters. This support was seen as a way to alleviate the burden of organization and practical tasks of euthanasia practice, allowing them to prioritize more important aspects, such as social activities.

Chapter 5

Our analysis revealed seven themes. Each theme represents an overarching good practice, a broad principle, or an approach that underlies various good practices. We identified 28 good practices. The first theme concerns patient-centeredness, including the following good practices: a) continuously assessing and meeting patients’ needs and preferences, b) safeguarding patient autonomy, c) psychosocial support for patients, and d) spiritual-existential support for patients. The second theme centers on family-centeredness, including the following good practices: a) continuously assessing and meeting relatives’ needs and preferences, b) actively involving relatives, c) special attention to children and young adults, d) facilitating communication between patients and relatives, e) psychosocial support for relatives, f) anticipatory grief and bereavement care for relatives, and g) spiritual-existential support for relatives. The third theme focuses on safeguarding the psychosocial well-being of HCPs, including the following good practices: a) self-care, and b) special attention to the psychological well-being of colleagues. The fourth theme revolves around managing expectations in patients and relatives, including the following good practices: a) developing euthanasia literacy in patients and relatives, b) developing euthanasia preparedness in patients and relatives, and c) establishing clear arrangements with patients and relatives. The fifth theme concerns carefulness, including the following good practices: a) continuity of support, b) professional preparedness for the performance of euthanasia, c) carefulness in assessing eligibility for euthanasia, d) medical-technical carefulness, e) serenity during the performance of euthanasia, and f) professional knowledge and skills about euthanasia. The sixth theme focuses on a multidisciplinary approach, including the following good practices: a) multidisciplinary collaboration, b) clear communication between HCPs, and c) consulting and involving special expertise. The seventh theme revolves around compassionate, proactive, and communicative HCPs, including the following good practices: a) being a compassionate HCP, b) being a proactive HCP, and c) being a communicative HCP.

Chapter 6

We identified five frames that form the basis for these variations in physicians' views and reasoning regarding control measures for CDS. The first frame concerns 'control through expertise', in which physicians propose expert consultation and training and/or education to improve CDS practice. The second frame focuses on 'strict due care', in which physicians put forward registration of CDS and shared decision-making to improve CDS practice. The third frame involves 'safeguarding patient choice', in which physicians advocate for having the legal option to initiating CDS to accompany the dying process of patients to improve CDS practice. The fourth frame centers around 'facilitating dignity', in which physicians propose to legally protect physicians who initiate CDS to facilitate a dignified dying process for patients with a severe loss of mental capacity to improve CDS practice. The fifth frame concerns' improving communication', in which physicians advocate for refining and improving physicians' communication skills and raising public awareness to improve CDS practice.

Overall, we identified two types of environmental factors affecting the CDS practices of physicians. First, we identified structural factors on the meso and macro level: the lack of professional and/or technical support in monitoring sedated patients; the use of guidelines in team contexts; the time constraints for treating individual patients and work pressure; the structural knowledge gap in medical education; the legal context for assisted dying; and the lack of a clear legal context for CDS. Second, we also identified cultural factors on the meso and macro level: the moral reservations of care teams and/or institutions towards CDS; the presence of a palliative care culture within care teams and institutions; the culture of fear of making clinical errors regarding CDS among a group of physicians; the professional stigma of performing assisted dying among some of the physician population; the different understandings of CDS in medical and policy fields; and the societal taboo around suffering at the end of life and natural death.

Interpretation of dissertation findings

A variety of potential problems and complexities: does it require a multi-solution and more integrated approach?

Our studies on euthanasia indicate that physicians can encounter several complexities in their euthanasia practices. As such, we found that complex requests are significantly less likely to result in the performance of euthanasia compared with non-complex requests. The complexity of a euthanasia request seems to be predominantly linked to assessing the substantive requirements (patient’s eligibility for euthanasia). However, complexity goes beyond the assessment of substantive requirements. Furthermore, physicians may also experience complexities on the day and during the act of performing euthanasia, such as medical-technical and psychosocial complexities.

The findings of this dissertation also show that physicians can encounter various problems in their CDS practices. First, physicians identify problems related to themselves and other physicians, for example, some physicians lack the required expertise to perform engage in CDS, and physicians face time constraints in monitoring the depth of the sedation. Second, physicians also note problems concerning relatives, for example, relatives sometimes exert pressure on physicians to perform CDS in patients with severe loss of mental capacity. Third, physicians experience problems concerning patients, for example, patients nearing death often request to receive CDS to have a ‘peaceful’ death to avoid potential suffering.

Participants across all our qualitative studies clearly state that problems or complexities only occur in the minorities of cases. Physicians and other HCPs report experiencing personal and professional satisfaction from involvement in these practices, despite the inherent intensity of it.

The variety of potential complexities and problems seems to imply the need for a corresponding variety of solutions (actions, control measures, or good practices) to counter these. This is supported by our findings in the CDS Study as physicians propose various solutions, actions, and control measures to improve CDS practice. For example, physicians point out that indicate that improper assessments for CDS can be addressed by seeking expert advice or expert consultation, training attending physicians, implementing CDS registration, and deploying a shared decision-making process involving multiple professionals. Furthermore, this is also supported by our findings in the Good Practices Study as HCPs report deploying multiple good practices partly to address and anticipate (potential) complexities and problems in euthanasia practice. In other words, this dissertation suggests that a multi-solution (combination of multiple solutions) and integrated (aligning them with each other) approach is more likely to effectively address one or multiple problems at hand than relying on a single solution.

How patients requesting euthanasia and their relatives view and experience euthanasia practice

This dissertation suggests that patients requesting euthanasia and their relatives experience euthanasia practice as a multidimensional and dynamic process, primarily characterized by physical-functional, psycho-existential, and social-relational dimensions (or dynamics). Thus, patients requesting euthanasia and their relatives can be argued not to differ substantially from those in other end-of-life trajectories, particularly in terms of their support needs. In addition, this dissertation also highlights the importance of involving relatives in euthanasia practice. This is partly materialized in our finding that patients requesting euthanasia and their relatives have a strong desire for social connectedness and meaningful interactions with each other throughout the euthanasia trajectory.

The Support Needs Study showed that relatives require support to understand the patient’s desire for euthanasia, which enables them to comprehend the broader and holistic context of the suffering as attending physicians tend to explain the patient’s unbearable suffering solely from a medical standpoint. Thus, this along with our findings that euthanasia is experienced as a multidimensional and dynamic process and that involving relatives is important**,** suggest a partially demedicalized support approach is beneficial for patients and relatives. This involves an optimal equilibrium between 1) a medical approach that is required by the legal requirements and the need for impeccable performance, and 2) a partially demedicalized support approach with physical-functional, psycho-existential, and social-relational components to fulfill the multidimensional needs of patients and their relatives.

The spectrum of professional involvement as support practice: unity makes strength?

This dissertation indicates that, in euthanasia and CDS practices, there exists a spectrum of professional involvement as support practice. This refers to involving as attending physician at least one additional HCP as a form of support, and which goes beyond assessing the legal requirements by a consultant in the case of euthanasia. This further suggests that professional involvement may hold substantial value, and in some cases, can be deemed as an essential precondition to ensure good practices.

Our studies on CDS found that physicians assign a prominent role to professional involvement in CDS practice due to its added value. As such, some physicians view professional involvement as essential for improving CDS practice. Therefore, these physicians advocate for mandatory peer consultation, based on their reasoning that CDS practice could be substantially improved by consulting experts for the assessment of medical indications, and by involving multiple HCPs in a shared decision-making process to ensure strict adherence to medical indications for CDS. Moreover, they indicate deploying these forms of professional involvement in their own CDS practices.

Our findings indicate that the mandatory peer consultations for a euthanasia request assessment are functioning as support practices (i.e., practices addressing the support needs of attending physicians) in addition to their functioning as control practices (i.e., practices merely for seeking advice on the fulfillment of legal requirements). This is substantiated in our finding that about one out of three attending physicians pose additional questions to LEIF consultants, and that a substantial proportion of attending physicians request LEIF consultants to assist in performing euthanasia and to carry out the performance of euthanasia. Thus, peer consultation in the context of euthanasia seems to function as a 'Swiss army knife', a tool accommodating the specific needs of attending physicians. In addition, we also found that multidisciplinary collaboration functions as a support practice, and is identified by HCPs as a good practice. More specifically, multidisciplinary collaboration is mainly deployed for assessing euthanasia requests, and supporting patients and relatives in their euthanasia trajectories. Attending physicians rely on multidisciplinary collaboration for these purposes to leverage specific expertise they lack.

This dissertation also presents evidence that palliative care involvement can offer additional benefits in the context of euthanasia practice. First, palliative HCPs can be argued to be well-positioned to effectively address the multidimensional support needs of patients requesting euthanasia and their relatives. Second, several overarching good practices in euthanasia closely align with the principles of a palliative care approach and the particular expertise of palliative HCPs, such as patient-centeredness, family-centeredness, and compassionate, proactive, and communicative HCPs. Third, attending physicians and other HCPs endorse multi-professional and multidisciplinary collaborations in euthanasia practice. This resonates with the holistic and multidisciplinary approach to palliative care, which emphasizes collaborative efforts among professionals from diverse disciplines, including medicine, nursing, social work, psychology, and others. Hence, we argue that euthanasia and palliative care should not be viewed as opposing practices but complementary ones. Thus, the Belgian model, which integrates both practices ('integral palliative care') seems empirically justified as this integration most likely provides better support for patients requesting euthanasia, their relatives, and attending physicians.

The potential psychological strains and burdens among HCPs

This dissertation shows that involvement in euthanasia and CDS practices can be accompanied by psychological strains and burdens among HCPs. In the context of euthanasia practice, physicians and other HCPs not only acknowledge a potential negative impact on their own psychological well-being due to their involvement, but also on the well-being of their colleagues. To mitigate this, HCPs deploy two good practices. The first good practice involves prioritizing self-care, such as setting moral boundaries and engaging in relaxing activities. The second good practice involves paying attention to the psychological well-being of colleagues. This includes serving as a supportive companion or confidant for colleagues and organizing debriefing sessions for open discussions and emotional support. In the context of CDs practice, some physicians in our studies report experiencing, for example, pressure from some relatives to perform CDS to hasten death in patients with severe mental impairment, and personal pressure to administer higher doses of sedation due to time constraints and a lack of professional support in monitoring the depth of sedation.

Implications and recommendations for practice and policy

- Adopt a well-coordinated and proactive support model for patients and relatives throughout their euthanasia trajectories, incorporating a patient-and-family-centered, partially demedicalized, and multidimensional approach
- Apply and facilitate multi-professional, multidisciplinary, and palliative care involvement in euthanasia and CDS practices
- Prioritize clear information, effective communication, and managing expectations as ways of patient and family empowerment in euthanasia and CDS practices
- Prioritize medical-technical and interpersonal knowledge and skills among attending physicians engaged in euthanasia and CDS practices to ensure high-quality practices
- Establish a shared and precise definition of CDS (practice)
- Monitor trends in end-of-life practices to inform evidence-based policies

Implications and recommendations for future research

- Conduct research to understand better how physicians make decisions regarding euthanasia and CDS
- Conduct more research with patients requesting euthanasia as research participants
- Conduct research to understand better the good practices in euthanasia
- Conduct research to understand better the support trajectories of patients requesting euthanasia

Dutch summary

Introductie

In de afgelopen decennia zijn medisch begeleid sterven en continue diepe sedatie tot aan het overlijden (CDS) steeds meer prevalente medische levenseindepraktijken geworden. Medisch begeleid sterven verwijst naar de praktijk waarin lethale medicatie intentioneel wordt gebruikt om het leven van een patiënt te beëindigen op diens expliciet en vrijwillig verzoek. Deze praktijk omvat euthanasie en medische hulp bij zelfdoding. Bij euthanasie dient een andere persoon dan de patiënt, meestal een arts, de lethale medicatie toe. Bij medische hulp bij zelfdoding is het de patiënt zelf die de lethale medicatie toedient. Continue diepe sedatie (CDS) is een vorm van palliatieve sedatie. Het omvat de praktijk waarin sedativa intentioneel worden toegediend bij een patiënt om diens bewustzijn te verlagen teneinde het ondraaglijk lijden van refractaire symptomen te verlichten, waarbij het verlaagd bewustzijn vervolgens continue wordt aangehouden tot aan het overlijden. In België, schat men dat ongeveer 13% van alle overlijdens op jaarbasis wordt voorafgegaan door CDS, en 3% door euthanasie.

Ondanks de prevalentie van deze medische praktijken, heeft empirisch onderzoek aangetoond dat patiënten, familieleden en zorgprofessionals geconfronteerd kunnen worden met verschillende moeilijkheden en uitdagingen in deze praktijken. Deze moeilijkheden en uitdagingen worden deels gelinkt aan de controle en ondersteuning bij deze praktijken. Daarom is er een groeiende consensus dat zowel CDS als euthanasia baat hebben bij het beter begrijpen van deze controle- en ondersteuningspraktijken. Dat heeft geleid tot de twee doelstellingen van dit proefschrift: 1) het beschrijven van huidige controle- en ondersteuningspraktijken bij euthanasie en het exploreren van hun potentieel voor verbetering in Vlaanderen en Brussel, België; en 2) het beschrijven van huidige controle- en ondersteuningspraktijken bij CDS en het exploreren van hun potentieel voor verbetering in België.

Onderzoeksvragen

In het kader van deze twee doelstellingen, beoogt dit proefschrift de volgende onderzoeksvragen te beantwoorden:

1. A) Wat zijn de kenmerken en uitkomsten van consultaties voor het uitklaren van een euthanasieverzoek, zoals gerapporteerd door behandelende artsen? **(Hoofdstuk 2)**
2. B) Wat zijn de effecten van deze kenmerken en uitkomsten van deze consultaties op de uitvoeringen van euthanasie, zoals gerapporteerd door behandelende artsen? **(Hoofdstuk 2)**
3. Wat zijn de (kwaliteits)kenmerken van consultaties voor het uitklaren van een euthanasieverzoek, en de veranderingen inzake deze kenmerken doorheen de tijd in deze kenmerken, zoals gerapporteerd door LevensEinde Informatie (LEIF) consulenten? **(Hoofdstuk 3)**
4. Welke ondersteuningsnoden ervaren patiënten met een euthanasieverzoek en hun naasten tijdens hun euthanasietrajecten? **(Hoofdstuk 4)**
5. Welke goede praktijken passen zorgprofessionals toe in de euthanasiepraktijk? **(Hoofdstuk 5)**
6. Hoe framen artsen controlemaatregelen rond continue diepe sedatie tot aan het overlijden? **(Hoofdstuk 6)**
7. Wat zijn de ervaringen en percepties van artsen rond de omgevingsfactoren die hun praktijken van continue diepe sedatie tot aan het overlijden beïnvloeden? **(Hoofdstuk 7)**

Methoden

We hebben vier studies uitgevoerd om deze onderzoeksvragen te beantwoorden. Deze studies bestaan uit vier verschillende dataverzamelingen, bestaande uit kwantitatief en kwalitatief onder. Kwantitatief onderzoek werd gebruikt om onderzoeksvragen 1 en 2 te beantwoorden, terwijl kwalitatief onderzoek werd gebruikt om onderzoeksvragen 3, 4, 5 en 6 te beantwoorden. In de studies over euthanasie (eerste doelstelling van het proefschrift), hebben we data van Vlaanderen en Brussel bestudeerd. In de studies over CDS (tweede doelstelling van het proefschrift), hebben we data van België bestudeerd.

LevensEinde Informatie Studie

Om de eerste onderzoeksvraag van dit proefschrift te beantwoorden, hebben we een cross-sectionele enquête studie uitgevoerd in Vlaanderen en Brussel, bij behandelende artsen die 1) een euthanasieverzoek hebben uitgeklaard in het jaar voorafgaand aan de enquête, en 2) daartoe een LEIF-consulent hebben geraadpleegd als de wettelijk vereiste tweede of derde arts. De data werden verzameld van september 2019 tot mei 2020. Om de kenmerken van de consultaties te onderzoeken, hebben we beschrijvende analyses uitgevoerd. Om de effecten van de kenmerken van deze consultaties op de uitvoeringen van euthanasie te onderzoeken, hebben we univariate logistische regressieanalyses uitgevoerd.

Om de tweede onderzoeksvraag van dit proefschrift te beantwoorden, hebben we een herhaalde cross-sectionele enquête studies uitgevoerd bij LEIF consulenten in Vlaanderen en Brussel, België. In de eerste enquête studie werden data verzameld van mei tot september 2008. In de tweede enquête studie hebben we data verzameld van september 2019 tot mei 2020. We hebben beschrijvende analyses uitgevoerd om de (kwaliteits)kenmerken van consultaties voor het uitklaren van euthanasieverzoeken te onderzoeken. Om veranderingen in deze kenmerken doorheen de tijd (tussen 2008 en 2019) te identificeren, hebben Fisher’s exact testen (2×2 tabel), Fisher-Freeman-Halton exact testen (2×3 tabel), en Pearson χ^2 testen uitgevoerd.

Ondersteuningsnoden Studie

Om de derde onderzoeksvraag van dit proefschrift te beantwoorden, hebben we een verkennende, kwalitatieve studie uitgevoerd in Vlaanderen en Brussel, bestaande uit 1) semigestructureerde interviews met patiënten met een euthanasieverzoeken en hun naasten, en 2) persoonlijke narratieven van patiënten met een euthanasieverzoek door middel van kwalitatieve vragenlijsten. Tussen december 2021 en september 2022 verzamelden we de data. Nadien hebben we een interpretatieve thematische analyse uitgevoerd.

Goede Praktijken Studie

Om de vierde onderzoeksvraag van dit proefschrift te beantwoorden, hebben we een kwalitatieve studie uitgevoerd, bestaande uit semigestructureerde interviews, focusgroepen en een expertpanel met zorgverleners die ervaring hebben met de euthanasiepraktijk in Vlaanderen en Brussel. Tussen januari en september 2022 hebben we de data verzameld. Vervolgens hebben we een interpretatieve thematische analyse uitgevoerd.

CDS Studie

Om de vijfde onderzoeksvraag van dit proefschrift te beantwoorden, hebben we een verkennende, kwalitatieve interviewstudie uitgevoerd met artsen die ervaring hebben met de CDS praktijk in België. We hebben semigestructureerde interviews afgenomen bij artsen van februari tot mei 2019. Om de data te analyseren, hebben we kwalitatieve framing analyse uitgevoerd. Om de zesde onderzoeksvraag van dit proefschrift te beantwoorden, hebben we een secundaire kwalitatieve analyse uitgevoerd op data van de semigestructureerde interviews.

Resultaten

Hoofdstuk 2

Onze bevindingen toonden aan dat het overgrote merendeel van de behandelende artsen huisartsen waren (92%). Meer dan de helft van de consultaties betrof patiënten met kanker (57%), terwijl 66% van de consultaties patiënten van 70 jaar of ouder betrof. De meest aangehaalde redenen voor patiënten om euthanasie te vragen waren lijden zonder uitzicht op verbetering (49%), verlies van waardigheid (11%), pijn (9%), en levensmoeheid (9%). In de overgrote meerderheid van de consultaties (85%) werden de LEIF consultenten geraadpleegd vanwege hun expertise. In bijna de helft van de consultaties (46%) werden ze geraadpleegd vanwege hun onafhankelijkheid (een wettelijke vereiste). In 91% van de consultaties gaven de LEIF consulenten een positief advies gegeven, d.w.z. de patiënt voldeed aan de inhoudelijke vereisten. Euthanasie werd uitgevoerd in acht van de tien consultaties (80%). We vonden dat de kans op het uitvoeren van euthanasie hoger was bij consultaties waarbij verlies van waardigheid, verlies van onafhankelijkheid in het dagelijks leven, of algemene zwakte en/of moeheid redenen waren voor het euthanasieverzoek, in vergelijking met consultaties zonder deze redenen. Bovendien bleken consultaties voor patiënten met een psychiatrische aandoening, significant minder kans hadden te leiden tot uitvoeringen van euthanasie, vergeleken met consultaties voor patiënten met kanker.

Hoofdstuk 3

In 2019, vergeleken met 2008, was er een aanzienlijke toename in de proportie LEIF consulenten die jonger waren dan 40 jaar (25% in 2019 vs. 10% in 2008, p=0.006) en die ten minste 60 jaar oud waren (34% in 2019 vs. 20% in 2008, p=0.006). Met betrekking tot hun activiteiten rond het uitklaren van euthanasieverzoeken over 12 maanden, vonden we een significante daling in de proportie patiënten die niet voldeden aan de wettelijke vereisen voor euthanasie in 2019 vergeleken met 2008 (42% in 2019 vs. 60% in 2008, p=0.020). In hun meest recente uitklaringen van euthanasieverzoeken, voerden LEIF consulenten significant meer uitklaringen uit voor patiënten van 80 jaar of ouder dan in 2008 (31% in 2019 vs. 9% in 2008, p<0.002). Daarentegen was er een significante daling in de proportie uitklaringen voor patiënten met kanker (53% in 2019 vs. 70% in 2008, p=0.034). Met betrekking tot het toepassen van kwaliteitscriteria voor consultatie in hun meest recente uitklaringen, gingen LEIF consulenten in 2019 significant vaker in op de volgende onderwerpen dan in 2008: ondraaglijk lijden (87% in 2019 vs. 65% in 2008, p=0.003) en alternatieve behandelingen, zijnde palliatieve zorg (48% in 2019 vs. 13% in 2008, p<0.001) en curatieve behandelingen (28% in 2019 vs. 5% in 2008, p=0.002).

Hoofdstuk 4

We identificeerden acht types van ondersteuningsnoden. Ten eerste hadden patiënten ondersteuning nodig om hun dagelijkse functioneren te maximaliseren, zoals hulp bij vervoer. Deze ondersteuning werd als noodzakelijk gezien om hun eigenwaarde te behouden en hen in staat te stellen om onafhankelijk thuis te blijven voor de uitvoering van euthanasie. Ten tweede hadden familieleden ondersteuning nodig om de wens van de patiënt voor euthanasie te begrijpen. Deze ondersteuning werd gezien als een manier om de euthanasie gemakkelijker een plaats te kunnen geven en hun eigen rol in het verlichten van het lijden te evalueren. Ten derde hadden de deelnemers ondersteuning nodig bij het uitvoeren van zinvolle activiteiten om hun resterende tijd samen te maximaliseren en zin te geven aan hun euthanasietrajecten, bijvoorbeeld ondersteuning bij het organiseren van een afscheidsritueel. Ten vierde hadden deelnemers ondersteuning nodig bij het navigeren van existentiële vragen, aangezien deze vragen kunnen leiden tot gevoelens van eenzaamheid en stress. Ten vijfde hadden deelnemers ondersteuning nodig voor psycho-emotionele regulatie, aangezien hun euthanasietrajecten vaak gekenmerkt worden door intense emoties, zoals angst. Ten zesde hadden deelnemers ondersteuning nodig om sociale interactie te faciliteren. Deelnemers hadden dit nodig om sociale conflicten op te lossen, sociale banden te verbeteren, communicatie met dierbaren te verbeteren, en betrokkenheid van naasten te faciliteren. Ten zevende hadden deelnemers ondersteuning nodig om het proces richting euthanasie te begrijpen. Deze ondersteuning zou hen een beter begrip geven van de euthanasiewetgeving en procedure, en inzicht geven in de besluitvorming rond euthanasia van de behandelende arts. Ten achtste hadden deelnemers ondersteuning nodig bij het omgaan met organisatorische en praktische zaken. Deze ondersteuning werd gezien als een manier om hen te ontlasten van organisatorische en praktische taken, waardoor ze meer tijd zouden hebben voor andere belangrijke aspecten, zoals sociale activiteiten.

Hoofdstuk 5

We identificeerden zeven thema's. Elk thema vertegenwoordigt een overkoepelende goede praktijk, een breed principe, of een benadering die ten grondslag ligt aan verschillende goede praktijken. We identificeerden 28 goede praktijken. Het eerste thema betreft patiëntgerichtheid, bestaande uit volgende goede praktijken: a) continu exploreren van en tegemoet komen aan de noden en voorkeuren van patiënten, b) het waarborgen van de autonomie van patiënten, c) psychosociale ondersteuning voor patiënten, en d) spiritueel-existentiële ondersteuning voor patiënten. Het tweede thema is gericht op familiegerichtheid, bestaande uit de volgende goede praktijken: a) continu exploreren van en tegemoet komen aan de noden en voorkeuren van naasten, b) actieve betrekken van naasten, c) speciale aandacht voor kinderen en jongvolwassenen, d) bevorderen van communicatie tussen patiënten en naasten, e) psychosociale ondersteuning voor naasten, f) het anticiperend op rouw en aanbieden van rouwzorg voor naasten, en g) spiritueel-existentiële ondersteuning voor naasten. Het derde thema is gericht op het waarborgen van het psychosociale welzijn van zorgverleners, bestaande uit de volgende goede praktijken: a) zelfzorg, en b) speciale aandacht voor het psychologische welzijn van collega's. Het vierde thema draait rond het bijstellen van verwachtingen bij patiënten en familieleden, bestaande uit volgende goede praktijken: a) ontwikkelen van euthanasie geletterdheid bij patiënten en familieleden, b) ontwikkelen van euthanasie gereedheid bij patiënten en familieleden, en c) duidelijke afspraken maken met patiënten en familieleden. Het vijfde thema betreft zorgvuldigheid, bestaande uit volgende goede praktijken: a) continuïteit van ondersteuning, b) professionele gereedheid voor de uitvoering van euthanasie, c) zorgvuldigheid bij het uitklaren van de wettelijke vereisten, d) medisch-technische zorgvuldigheid, e) sereniteit tijdens de uitvoering van euthanasie, en f) professionele kennis en vaardigheden inzake euthanasie. Het zesde thema is gericht op een multidisciplinaire aanpak, bestaande uit volgende goede praktijken: a) multidisciplinaire samenwerking, b) duidelijke communicatie tussen zorgverleners, en c) raadplegen en betrekken van speciale expertise. Het zevende thema draait om compassievolle, proactieve, en communicatieve zorgverleners, bestaande uit volgende goede praktijken: a) een compassievolle zorgverlener zijn, b) een proactieve zorgverlener zijn, en c) een communicatieve zorgverlener zijn.

Hoofdstuk 6

We hebben vijf denkkaders geïdentificeerd bij artsen die betekenis geven aan controlemaatregelen voor euthanasie. Het eerste denkkader betreft 'controle door expertise', waarin artsen het consulteren van experten en training en/of educatie vooropstellen om de CDS praktijk te verbeteren. Het tweede denkkader richt zich op 'strikte zorgvuldigheid', waarin artsen de registratie van CDS en gedeelde besluitvorming naar voren schuiven om de CDS praktijk te verbeteren. Het derde denkkader betreft 'het waarborgen van de keuze van de patiënt' om de CDS praktijk te verbeteren, waarin artsen pleiten voor het hebben van de wettelijke optie om CDS uit te voeren om het stervensproces van patiënten met verlies van te versnellen. Het vierde denkkader draait om 'waardigheid faciliteren', waarin artsen pleiten voor wettelijk bescherming om CDS te kunnen uitvoeren bij mensen met ernstig verlies van mentaal vermogen. Het vijfde denkkader betreft 'het verbeteren van de communicatie', waarin artsen pleiten voor het verfijnen en verbeteren van de communicatieve vaardigheden van artsen en het verhogen van het publieke bewustzijn rond CDS.

Hoofdstuk 7

We identificeerden twee soorten omgevingsfactoren die de CDS praktijken van artsen beïnvloeden. Ten eerste hebben we structurele factoren op meso- en macroniveau geïdentificeerd: het gebrek aan professionele en/of technische ondersteuning bij het monitoren van gesedeerde patiënten; het gebruik van richtlijnen in teams; de tijdsbeperkingen voor het behandelen van patiënten en de werkdruk; de structurele kenniskloof in artsenopleidingen; de juridische context voor euthanasie; en het ontbreken van een duidelijke juridische context voor het uitvoeren van CDS. Ten tweede hebben we ook culturele factoren op meso- en macroniveau geïdentificeerd: de morele terughoudendheid rond CDS bij teams en/of instellingen; de aanwezigheid van een palliatieve zorgcultuur binnen zorgteams en instellingen; de cultuur van angst voor het maken van klinische fouten rond CDS bij een groep van artsen; het professionele stigma rond het uitvoeren euthanasia bij een deel van de artsenpopulatie; de verschillende interpretaties van CDS in medische praktijk en in het beleidsdomen; en het maatschappelijke taboe rond lijden aan het levenseinde van het leven en de dood.

Interpretatie van de resultaten

Een verscheidenheid aan mogelijke problemen en complexiteiten: vereist dit geïntegreerde benadering bestaande uit meerdere oplossingen?

Onze studies over euthanasie geven aan dat artsen verschillende complexiteiten kunnen tegenkomen in hun euthanasiepraktijken. Zo vonden we dat complexe verzoeken aanzienlijk minder kans hebben te leiden tot uitvoeringen van euthanasie in vergelijking met niet-complexe verzoeken. De complexiteit van een euthanasieverzoek lijkt gerelateerd te zijn aan het uitklaren van de wettelijke vereisten. De complexiteit gaat echter verder dan enkel het uitklaren van wettelijke vereisten. Artsen kunnen immers ook complexiteiten ervaren op de dag de uitvoering en/of tijdens de uitvoering, zoals medisch-technische en psychosociale complexiteiten.

Verder toont dit proefschrift ook dat artsen verschillende problemen kunnen tegenkomen in hun CDS praktijken. Ten eerste, identificeren artsen problemen betreffende henzelf en andere artsen, bijvoorbeeld, sommige artsen missen de vereiste expertise om CDS uit te voeren, en artsen ervaren tijdsgebrek om de diepte van de sedatie te monitoren. Ten tweede, merken artsen ook problemen op met betrekking tot naasten, bijvoorbeeld, naasten oefenen soms druk uit op artsen om CDS uit te voeren bij patiënten met ernstig verlies van mentaal vermogen. Ten derde, ervaren artsen problemen met betrekking tot patiënten, bijvoorbeeld, patiënten aan het levenseinde vragen vaak om CDS uit te voeren teneinde een 'vreedzame' dood te krijgen en mogelijk lijden te vermijden.

Deelnemers aan al onze kwalitatieve studies geven duidelijk aan dat problemen of complexiteiten slechts voorkomen in de minderheid van gevallen. Artsen en andere zorgverleners melden persoonlijke en professionele tevredenheid te ervaren van betrokkenheid bij euthanasia en CDS praktijken, ondanks de inherente intensiteit van betrokkenheid.

De verscheidenheid aan mogelijke complexiteiten en problemen suggereert dat er een verscheidenheid aan oplossingen (acties, controlemaatregelen of goede praktijken) moet bestaan om deze tegen te gaan. Dit wordt bevestigd door onze bevindingen in de CDS Studie, waarin artsen verschillende oplossingen, acties en beheersmaatregelen voorstellen om de CDS praktijk te verbeteren. Bijvoorbeeld, artsen wijzen erop dat onjuiste beoordelingen voor CDS kunnen worden aangepakt door via het consulteren van experten inzake CDS, het trainen van behandelende artsen, het verplichten van CDS registratie en het inzetten op gedeelde besluitvorming met meerdere zorgverleners. Verder wordt dit ook bevestigd door onze bevindingen in de Goede Praktijken Studie, waarin zorgverleners aanhalen dat ze meerdere goede praktijken gebruiken, deels om (potentiële) complexiteiten en problemen in de euthanasiepraktijk aan te pakken en te anticiperen. Met andere woorden, dit proefschrift suggereert dat geïntegreerde benadering bestaande uit een combinatie van oplossingen en geïntegreerde meer effectiever kan zijn om één of meerdere problemen aan te pakken.

Hoe patiënten met een euthanasieverzoek en naasten hun euthanasiepraktijken percipiëren en ervaren

Deze dissertatie suggereert dat patiënten die om euthanasie verzoeken en hun naasten euthanasiepraktijken ervaren als een multidimensioneel en dynamisch proces, bestaande uit fysiek-functionele, psycho-existentiële en sociaal-relationele dimensies (of dynamieken). We menen dan ook dat patiënten met een euthanasieverzoek en hun naasten niet wezenlijk verschillen van patiënten en naasten in andere trajecten aan het levenseinde wanneer het aankomt op hun ondersteuningsbehoeften. Bovendien benadrukt dit proefschrift ook het belang van het betrekken van naasten bij de euthanasiepraktijk. Dat komt deels tot uiting in onze bevinding dat patiënten en hun naasten een sterke behoefte hebben aan sociale verbondenheid en betekenisvolle interacties met elkaar tijdens hun euthanasietrajecten.

Deze dissertatie toonde aan dat naasten ondersteuning nodig hebben om de euthanasiewens van de patiënt beter te begrijpen, aangezien behandelende artsen het ondraaglijke lijden van de patiënt voornamelijk vanuit een medisch standpunt benaderen. Dit, samen met onze bevindingen dat euthanasie wordt ervaren als een multidimensioneel en dynamisch proces en dat het betrekken van naasten belangrijk is, suggereert dat een deels gedemedicaliseerde ondersteuning gunstig kan zijn voor patiënten en hun naasten. Dat houdt onder meer een optimaal evenwicht in tussen 1) een medische aanpak die vereist omwille van de wettelijke eisen en een goede uitvoering, en 2) een deels gedemedicaliseerde ondersteuning met fysiek-functionele, psycho-existentiële en sociaal-relationele componenten om tegemoet te komen aan de multidimensionele noden van patiënten en hun naasten.

Het spectrum van professionele betrokkenheid als ondersteuningspraktijk: eendracht maakt macht?

Deze dissertatie geeft aan dat er bij euthanasie en CDS praktijken een spectrum van professionele betrokkenheid bestaat als ondersteuningspraktijk. Dit verwijst naar de betrokkenheid van ten minste één extra gezondheidszorgprofessional door de behandelend arts als vorm van ondersteuning, en die verder gaat dan het uitklaren van de wettelijke eisen door een consulent in het geval van euthanasie. Dit suggereert dat professionele betrokkenheid een aanzienlijke meerwaarde kan hebben en in sommige gevallen kan worden beschouwd als een essentiële voorwaarde om goede praktijken te waarborgen.

Onze studies over CDS hebben uitgewezen dat artsen een prominente rol toekennen aan professionele betrokkenheid in de CDS praktijk vanwege de toegevoegde waarde ervan. Sommige artsen beschouwen professionele betrokkenheid als essentieel voor het verbeteren van de CDS praktijk. Daarom pleiten deze artsen voor verplichte consultatie, gebaseerd op de redenering dat de CDS-praktijk aanzienlijk verbeterd kan worden door experts te raadplegen voor de beoordeling van medische indicaties, en door meerdere zorgverleners te betrekken via een gedeeld besluitvormingsproces om de strikte naleving van de medische indicaties te kunnen waarborgen. Bovendien geven artsen aan dat ze deze vormen van professionele betrokkenheid toepassen in hun eigen CDS praktijken.

Dit proefschrift suggereert dat de verplichte consultaties voor het uitklaren van een euthanasieverzoek functioneren als ondersteuningspraktijken (d.w.z. praktijken die de ondersteuningsnoden van de behandelende artsen invullen), naast hun functie als controlepraktijken (d.w.z. praktijken die controleren of het euthanasieverzoek voldoet aan de wettelijke eisen). Dit zien we onder meer terug in onze bevinding dat ongeveer één op de drie behandelende artsen extra vragen stelt aan de LEIF consulenten, en dat een aanzienlijk deel van de behandelende artsen aan de LEIF consulenten vraagt om te helpen bij het uitvoeren van euthanasie en ook vragen om het uit te voeren. De consultaties voor een euthanasieverzoek lijken dus te functioneren als een 'Zwitsers zakmes', een hulpmiddel dat inspeelt op de specifieke ondersteuningsnoden van de behandelende artsen. Daarnaast vonden we ook dat multidisciplinaire samenwerking functioneert als een ondersteuningspraktijk en door zorgverleners wordt geïdentificeerd als een goede praktijk. Meer specifiek wordt multidisciplinaire samenwerking voornamelijk ingezet voor het uitklaren van euthanasieverzoeken en voor het ondersteunen van patiënten en hun naasten in hun euthanasietrajecten. Behandelende artsen vertrouwen op multidisciplinaire samenwerking voor deze doeleinden om specifieke expertise te benutten die ze zelf missen.

Deze dissertatie toont ook aan dat de betrokkenheid van palliatieve zorg meerwaarde kan bieden in de context van euthanasie. Ten eerste zijn palliatieve zorgverleners uiterst geschikt om de multidimensionele ondersteuningsnoden van patiënten met een euthanasieverzoek en hun naasten effectief aan te pakken. Ten tweede sluiten verschillende algemene goede praktijken bij euthanasie nauw aan bij de principes van een palliatieve zorg en de specifieke expertise van palliatieve zorgverleners, zoals patiëntgerichtheid, familiegerichtheid, en meelevende, proactieve en communicatieve zorgverleners. Ten derde ondersteunen behandelende artsen en andere zorgverleners multidisciplinaire samenwerkingen bij euthanasie. Dit sluit aan bij de holistische en multidisciplinaire aanpak van palliatieve zorg, waarin professionals uit diverse disciplines samenwerken, waaronder geneeskunde, verpleegkunde, maatschappelijk werk, en psychologie. Daarom menen we dat euthanasie en palliatieve zorg dat complementaire praktijken zijn. Het Belgische model, dat beide praktijken integreert lijkt daarom empirisch gerechtvaardigd, omdat deze integratie betere ondersteuning kan bieden voor patiënten, hun naasten en behandelende artsen.

De mogelijke psychologische impact bij zorgverleners

Deze dissertatie toont aan dat professionele betrokkenheid bij euthanasie en CDS praktijken gepaard kan gaan met psychologische belastingen en impact bij zorgverleners. In de context van euthanasiepraktijken erkennen artsen en andere zorgverleners niet alleen een mogelijke negatieve impact op hun eigen psychologisch welzijn, maar ook op het welzijn van hun collega's. Om dit te reduceren, hanteren zorgverleners twee goede praktijken. De eerste goede praktijk omvat zelfzorg, zoals het stellen van morele grenzen en het deelnemen aan ontspannende activiteiten. De tweede goede praktijk houdt in dat er aandacht is voor het psychologische welzijn van collega's. Dit omvat optreden als een ondersteunende gesprekspartner of vertrouwenspersoon voor collega's en het organiseren van debriefingsessies voor open discussies en emotionele ondersteuning. In de context van CDS praktijken rapporteren sommige artsen in onze studies dat zij bijvoorbeeld druk ervaren van sommige naasten om CDS uit te voeren om het stervensproces te bespoedigen bij patiënten, en de persoonlijke druk ervaren om hogere dosissen van sedativa toe te dienen vanwege gebrek aan tijd en professionele ondersteuning tijdens het monitoren van CDS.

Implicaties en aanbevelingen voor de medische praktijk en het beleid

- Bied gecoördineerde en proactieve ondersteuning aan voor patiënten en hun naasten doorheen hun euthanasietrajecten, en maak daarbij gebruik van een patiënt- en familiegerichte, deels gedemedicaliseerde, en multidimensionale benadering
- Zet in op en faciliteer professionele betrokkenheid, multidisciplinaire samenwerking, en het betrekken van palliatieve zorg in euthanasie en CDS-praktijken
- Zet in op duidelijke informatie, effectieve communicatie en het bijstellen van verwachtingen in euthanasie en CDS praktijken om patiënten en naasten te empoweren
- Zet in op medisch-technische en interpersoonlijke kennis en vaardigheden bij behandelende artsen in euthanasie en CDS-praktijken om de kwaliteit van deze praktijken te waarborgen
- Definieer CDS en de CDS praktijk
- Monitor trends in levenseindepraktijken voor het ontwikkelen van beleid

Implicaties en aanbevelingen voor toekomstig onderzoek

- Voer onderzoek uit om beter te begrijpen hoe artsen beslissingen nemen rond euthanasie en CDS
- Voer meer onderzoek uit met patiënten met een euthanasieverzoek
- Voer onderzoek uit om de goede praktijken bij euthanasie beter te begrijpen
- Voer onderzoek uit om de ondersteuningstrajecten van patiënten met een euthanasieverzoek beter te begrijpen

ACADEMIC CURRICULUM VITAE

About the author

Stijn Vissers completed his Master’s degree in Sociology at Ghent University and the University of Salamanca in Spain. He began his academic career in 2018 as a scientific researcher within the ‘Organisation, Policy & Inequalities in Healthcare Research Group’ at Vrije Universiteit Brussel, to conduct policy research on the organization of care and support for children and adults with autism spectrum disorders in Flanders. Afterwards, he joined the interuniversity End-of-Life Care Research Group (Ghent University and the Vrije Universiteit Brussel) as a PhD researcher in 2019. His PhD research, under the supervision of Prof. Luc Deliens, Prof. Kenneth Chambaere, Prof. Joachim Cohen, and Dr. Sigrid Dierickx, focused on the medical practices of euthanasia and palliative sedation in Belgium. The findings of his PhD research have been published in international peer-reviewed journals and were presented at national and international conferences. He received the ‘Award Cancer Research 2022’ from the Oncology Center of Vrije Universiteit Brussel for the relevance of his research in the field of cancer care. Based on his dissertation findings, he is developing an evidence-based practice guide for euthanasia for physicians in Belgium, supported by Vrije Universiteit Brussel Scientific Fund. He has been awarded a Fulbright Postdoctoral Fellowship to conduct a follow-up study on family caregivers' experiences with physician aid-in-dying practices in home settings in the United States. This research will be carried out at the Center for Research on End-of-Life Care, Weill Cornell Medicine and New York-Presbyterian University Hospital, under the supervision of Prof. Holly Prigerson, starting in December 2023.

Research presentations at (inter)national conferences

2023	‘*Experience-based Support Needs of Patients Requesting Euthanasia and their Relatives: An In-depth Interview Study of Lived Experiences’.* The 18th EAPC World Congress 2023, the Netherlands. [Poster presentation]
2022	‘*What are patients’ motives for requesting euthanasia? A cross-sectional survey among attending physicians’.* The 12th European Association for Palliative Care (EAPC) World Research Congress, online. [Oral presentation]
	‘Shifts in characteristics and quality of peer consultations with Life End Information Forum (LEIF) consultants to assess an assisted dying request between 2008 and 2019:

repeated cross-sectional survey'. Dutch-Flemish Science Days Palliative Care 2022, the Netherlands. [Oral Presentation]

'Physicians perceptions and experiences of environmental factors affecting their practices of continuous deep sedation until death: a qualitative secondary analysis of an interview study'. Dutch-Flemish Science Days Palliative Care 2022, the Netherlands. [Oral Presentation]

2021 *'Cultural and structural factors affecting physicians' decision making and performance of continuous deep sedation until death: an environmental context analysis of experiences of physicians'.* The 17th World Congress of the European Association for Palliative Care (EAPC), online. [Poster presentation]

'Shifts in consultation of specially trained physicians in the context of a euthanasia request: a repeated cross-sectional survey, 2008 versus 2019'. The 17th World Congress of the European Association for Palliative Care, online. [Poster presentation]

2020 *'Control measures for continuous deep sedation until death: a frame analysis of physicians' views'.* The 11th European Association for Palliative Care (EAPC) World Research Congress, online. [Oral presentation]

2019 *'Control measures for continuous deep sedation until death: a frame analysis of physicians' views'.* Dutch-Flemish Science Days Palliative Care 2019, Antwerp, Belgium. [Poster presentation]

'Control measures for continuous deep sedation until death: a frame analysis of physicians' views'. Research Seminar on Assisted Dying of International Conference on End-of-Life Law, Ethics, Policy, and Practice 2019, Ghent, Belgium. [Oral presentation]

2018 *'Case-study of the iatrogenic stigma process in patients with schizophrenia: an ethnographic study in a psychiatric hospital'.* Research Seminar on Stigma in patients with psychiatric conditions, Brussels, Belgium. [Oral presentation]

Peer-reviewed publications

Vissers, S., Dierickx, S., Deliens, L., Mortier, F., Cohen, J., & Chambaere, K. (2023). Characteristics and outcomes of peer consultations for assisted dying request assessments: Cross-sectional survey study among attending physicians. Frontiers in Public Health, 11, 1100353.

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Vissers S., Gilissen J., Cohen J., Deliens L., Mortier F., Chambaere K., Dierickx. S. Support needs experienced by patients requesting euthanasia and relatives throughout the euthanasia trajectory: a qualitative study using semi-structured interviews and written narratives. 2023. (Submitted)

Vissers S., Gilissen J., Cohen J., Deliens L., Mortier F., Chambaere K., Dierickx S. Experience-based good practices in euthanasia: a qualitative study of the lived experiences of healthcare professionals. (Submitted)

Commissioned policy reports

Vissers S., Robijn L., Verhofstadt M., Chambaere K. Evaluation of complex medical end-of-life decisions in Belgium. 2019. Belgium Federal Public Services of Health. Belgian Federal Public Service of Health.

Leys M., Vissers S., Cloet E. Interorganizational and multidisciplinary collaboration for persons with Autism Spectrum Disorder: towards more integration of care in Flanders. 2019. Steunpunt Welzijn, Volksgezondheid en Gezin.

Academic honors, awards, and fellowships

2023	Fulbright Postdoctoral Fellowship-2023
2022	Award Cancer Research-2022 of the VUB Oncology Research Center
2021	Hercules Award-2021 of the VUB Scientific Support Fund