

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

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## Abstract

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

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

**Design:** Population-based mortality follow-back survey.

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

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

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

## Keywords

Palliative care, euthanasia, end-of-life care, end-of-life decision-making

### What is already known about the topic?

1. It is commonly stated that euthanasia and physician-assisted suicide are incompatible with good palliative care.
2. Palliative care practice in those jurisdictions where medically assisted dying is legal is faced with questions about how people who are receiving palliative care can access medically assisted dying.
3. Population-based evidence on the actual involvement of palliative care services in euthanasia practice in a context of legalized euthanasia is currently lacking.

### What this paper adds?

1. People requesting euthanasia were more likely to have received palliative care than other people dying non-suddenly.

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2. The likelihood of a euthanasia request being granted did not differ between cases where palliative care was involved in end-of-life care and cases where it was not.
3. Palliative care professionals were frequently involved in euthanasia procedures, both in consultation about euthanasia requests and in the performance of euthanasia.

#### **Implications for practice, theory or policy**

1. Access to palliative care does not seem to prevent requests for euthanasia or those requests being granted.
2. In a context of legalized euthanasia, health professionals working in palliative care are likely to be confronted frequently with euthanasia requests, regardless of their attitudes toward assisting people in dying.
3. With an increasing number of people worldwide having the legal option of medically assisted dying, the question of how palliative care physicians and nurses respond to people requesting euthanasia is particularly relevant.

## **Introduction**

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

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

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

professionals active in all care facilities and palliative home care services organized in regional networks.

In Belgium, the option of euthanasia is not restricted to people with a terminal condition. People with a chronic, non-terminal disorder are also eligible for euthanasia, but these requests should adhere to the additional legal requirement of a 1-month waiting period between the euthanasia request and the performance of euthanasia.<sup>15</sup> For people requesting euthanasia because of a terminal disorder, no waiting period is required. The Belgian euthanasia law does not include a compulsory palliative care consultation; it does, however, require the physician to inform the patient of all available treatment options, including palliative care. The patient is not required to try palliative care as it is a patient's right to refuse treatment, including palliative care treatment.

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

## **Method**

### **Study design**

In 2013, we conducted a population-based mortality follow-back survey based on a large and representative sample of deaths ( $N=6871$ ) in Flanders, Belgium. This study

design has been repeatedly applied and validated in earlier studies evaluating end-of-life care and decision-making.<sup>16–18</sup> We obtained a stratified random sample of all death certificates from 1 January 2013 to 30 June 2013 of people aged 1 year or older from the Flemish Agency for Care and Health. The survey was conducted from 1 March 2013 to 31 December 2013. Every physician certifying a death certificate in the sample was requested to complete a four-page questionnaire about the end-of-life care and decision-making consulting the patient's medical file. A lawyer served as an intermediary between responding physicians, researchers, and the Flemish Agency for Care and Health, ensuring that completed questionnaires could never be linked to a patient or physician. A one-page questionnaire was mailed to all non-responding physicians, inquiring about the reasons for not participating. The Ethical Review Board of the University Hospital of the Vrije Universiteit Brussel, the Belgian National Disciplinary Board of Physicians, and the Belgian Privacy Commission approved the mailing and anonymity procedure. Further details on this study and the data collection procedure can be found in previous articles covering this dataset.<sup>2,16,19,20</sup>

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

### Questionnaire

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

Furthermore, in the questionnaire, physicians were asked whether one or more of the four types of palliative care services in Belgium had been involved in the end-of-life care of the deceased person: palliative care support at home (multidisciplinary teams skilled in palliative care who support the informal caregivers), hospital-based palliative care teams (mobile multidisciplinary teams that guide palliative care in the different wards of the hospital), inpatient palliative care units (separate wards in the hospital devoted to palliative care), and a

reference person (usually a nurse) trained in and responsible for palliative care in a nursing home. Where no palliative care services had been involved, the physician was asked about the reasons no such services were used. They were also asked whether one or more caregivers specialized in palliative care were consulted about euthanasia, whether death occurred in a palliative care unit, and whether the attending physician was part of a palliative care team. Demographic and clinical data were obtained from the death certificate and linked anonymously after data collection.

### Data analysis

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

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

### Results

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

**Table 1.** Involvement of palliative care services in the end-of-life care of non-sudden deaths without euthanasia request ( $n=2042$ ) and deaths with euthanasia request ( $n=415$ ).

	Non-sudden deaths without euthanasia request		Deaths with euthanasia request		<i>p</i> -value*	OR (95% CI) <sup>a</sup>
	Total, <i>n</i> (column %)	Palliative care services involved, %	Total, <i>n</i> (column %)	Palliative care services involved, %		
Overall		45.2		70.9	<0.001	<b>2.1 (1.5–2.9)</b>
Sex						
Male	1015 (48.1)	45.3	210 (50.7)	71.3	<0.001	<b>2.2 (1.4–3.4)</b>
Female	1024 (51.9)	45.0	205 (49.3)	70.5	<0.001	<b>2.1 (1.3–3.3)</b>
Age						
18–64	284 (12.3)	55.1	95 (21.4)	77.4	0.005	1.7 (0.8–3.3)
65–79	588 (26.6)	47.5	147 (34.7)	76.7	<0.001	<b>3.5 (1.9–6.6)</b>
80 or older	1167 (61.1)	42.1	173 (43.9)	63.2	<0.001	<b>1.9 (1.2–2.9)</b>
Cause of death						
Cancer	858 (28.9)	70.3	255 (56.7)	82.3	0.004	<b>1.9 (1.3–2.8)</b>
Non-cancer	1180 (71.1)	35.0	160 (43.3)	54.8	<0.001	<b>2.4 (1.5–3.9)</b>
Place of death						
Hospital	854 (50.7)	40.1	106 (39.6)	81.2	<0.001	<b>4.4 (2.3–8.5)</b>
Home	550 (19.1)	52.9	234 (42.4)	68.0	0.010	1.5 (0.9–2.3)
Nursing home	620 (29.6)	49.1	73 (17.6)	54.7	0.506	1.3 (0.7–2.4)
Other	14 (0.6)	34.7	2 (0.4)	79.9	0.400	<sup>b</sup>

OR: odds ratio; CI: confidence interval.

Involvement of palliative care services includes involvement of palliative care support at home, hospital-based palliative care service, palliative care unit, or palliative care reference person in a nursing home. Missing values: involvement of palliative care services:  $n=23$  (0.9%); sex:  $n=3$  (0.1%); age:  $n=3$  (0.1%); cause of death:  $n=4$  (0.2%); and place of death:  $n=4$  (0.2%).

\*Fisher exact test for differences in involvement of palliative care services in end-of-life care between non-sudden deaths without euthanasia request and deaths with euthanasia request.

<sup>a</sup>Complex sample multivariate logistic regression analyses with involvement of palliative care in end-of-life care as dependent variable (palliative care involved vs palliative care not involved) and presence of a euthanasia request, patient's sex, age, cause of death, and place of death as independent variables. Figures in bold denote significant results ( $p < 0.05$ ).

<sup>b</sup>Odds ratio could not be calculated.

an expressed euthanasia request, and 349 deaths (weighted percentage 4.6%) were the result of euthanasia.

Of all the people who used palliative care services, 14.1% had expressed a request for euthanasia (data not shown). Palliative care services were more likely to have been involved in the end-of-life care of those who requested euthanasia than of those who died non-suddenly without expressing a request for euthanasia (70.9% vs 45.2%, odds ratio (OR)=2.1 (95% confidence interval (CI), 1.5–2.9)), controlled for sex, age, cause of death, and place of death (Table 1). Palliative care services were more likely to have been involved particularly in the deaths of those who had requested euthanasia and were 65 to 79-years old (OR=3.5 (95% CI, 1.9–6.6) or were dying in hospital (OR=4.4 (95% CI, 2.3–8.5)).

For people who were not referred to a palliative care service, the most frequently indicated reason for non-referral was that existing care already sufficiently addressed the palliative and supportive care needs, both in those dying non-suddenly without having expressed a euthanasia request (48.3%) and those who had made a euthanasia request (56.5%) (Table 2). In 26.1% of people

with a euthanasia request, the reason for non-referral was that they did not want to be referred to a palliative care service, compared with 2.8% of those dying non-suddenly without having expressed a euthanasia request ( $p < 0.001$ ). Palliative care not being deemed meaningful was more often indicated as a reason for non-referral for people dying non-suddenly without having expressed a euthanasia request (34.7%) than in those who expressed a euthanasia request (21.7%) ( $p = 0.048$ ).

Overall, no significant differences were found between the likelihood of a euthanasia request being granted in cases where palliative care was involved in end-of-life care and those where it was not (Table 3). In people aged 80 years or older, the granting rate was significantly higher when palliative care was involved in end-of-life care: 83.4% of euthanasia requests were granted, compared with 69.4% when palliative care was not involved (OR=3.3 (95% CI, 1.1–9.6)).

Palliative care professionals were involved in the decision-making process and performance of euthanasia in 59.8% of all deaths by euthanasia (Table 4). In 52.4% of performed euthanasia cases, a palliative care professional

**Table 2.** Reasons given by physicians for not referring to palliative care services.

	Non-sudden deaths without euthanasia request not referred to palliative care (n=988), <sup>a</sup> %	Deaths with euthanasia request not referred to palliative care (n=126), <sup>a</sup> %	p-value*
Reasons given by physicians for not referring to palliative care services			
The care already sufficiently addressed the patient's palliative and supportive care needs	48.3	56.5	.226
Palliative care was not deemed meaningful	34.7	21.7	<b>.048</b>
There was not enough time to initiate palliative care	24.5	14.7	.118
The patient's family did not want it	3.2	5.8	.439
The patient did not want it	2.8	26.1	<b>&lt;0.001</b>
Palliative care was not available	1.0	1.0	.450
In order not to deprive the patient and/or family of hope	0.5	0.0	0.999

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

\*Fisher exact test for differences in reasons given by physicians for not referring to palliative care services between non-sudden deaths without euthanasia request and deaths with euthanasia request. Figures in bold denote significant differences ( $p < 0.05$ ).

<sup>a</sup>Of all non-sudden deaths without euthanasia request (n=2042), 988 were not referred to palliative care. Of all deaths with euthanasia request (n=415), 126 were not referred to palliative care.

**Table 3.** Euthanasia granting rates according to involvement of palliative care services.

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

Unweighted numbers and weighted row percentages.

<sup>a</sup>Complex sample multivariate logistic regression analyses with result of the euthanasia request as dependent variable (granted vs not granted) and involvement of palliative care services, patient's sex, age, cause of death, and place of death as independent variables. Figures in bold denote significant results ( $p < 0.05$ ).

<sup>b</sup>Odds ratio could not be calculated.

was consulted about the euthanasia request; in 21.1% of cases, the attending physician was part of a palliative care team; and in 17.4% cases, euthanasia was performed in a palliative care unit. Palliative care professionals were significantly more often consulted about the euthanasia request and the attending physician was more often part of

a palliative care team when the patient died in hospital. When palliative care professionals were involved in the decision-making and performance, the patient's mental suffering was more often indicated as one of the most important reasons for granting the request (50.9% vs 22.4%,  $p = 0.002$ ) (data not shown).

**Table 4.** The role of palliative professionals in the decision-making process and performance of euthanasia.<sup>a</sup>

	Deaths by euthanasia, <i>n</i>	Palliative care professionals involved in decision-making and/or performance of euthanasia, <sup>b</sup> %	Palliative care professional was consulted about the request, %	Palliative care professional involved in performance of euthanasia	
				Attending physician was part of a palliative care team, %	Euthanasia was performed in a palliative care unit, %
Overall	349	59.8	52.4	21.1	17.4
Sex					
Male	174	58.9	54.9	20.3	5.7
Female	175	60.7	49.9	21.9	9.1
Age					
18–64	73	66.2	54.3	23.6	9.6
65–79	131	60.1	51.0	24.8	11.9
80 or older	145	56.6	52.8	16.7	2.5
Cause of death					
Cancer	211	<b>68.0</b>	57.3	24.3	10.7
Non-cancer	138	<b>48.7</b>	46.0	16.8	3.0
Place of death					
Hospital	91	<b>76.0</b>	<b>65.5</b>	<b>38.0</b>	16.7
Home	197	<b>47.0</b>	<b>42.0</b>	<b>6.8</b>	0.0
Nursing home	60	<b>49.5</b>	<b>44.5</b>	<b>13.5</b>	0.0
Other <sup>c</sup>	1	100.0	100.0	0.0	0.0

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

<sup>a</sup>Figures in bold denote significant differences ( $p < 0.05$ ) after complex sample multivariate logistic regression analyses with involvement of palliative care professionals as dependent variable (involved vs not involved) and patient sex, age, cause of death, and place of death as independent variables.

<sup>b</sup>A palliative care professional was consulted about the euthanasia request, and/or the attending physician was part of a palliative care team and/or euthanasia was performed in a palliative care unit.

<sup>c</sup>Not included in the analysis.

## Discussion

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

While previous studies investigated referral to palliative care and reasons for non-referral<sup>19</sup> and expression and granting of euthanasia requests,<sup>2</sup> this is the first study focusing on the relationship between the two. Strengths of this study include the use of a mortality follow-back survey conducted among the attending physicians of a representative sample of deaths with a high response rate (61%). This study design is the most feasible and reliable way to study the care delivered shortly before death within a population and, hence, to collect population-based and generalizable information on end-of-life care. However, some study limitations should be considered. First, due to the retrospective nature of the data collection, recall bias

cannot be excluded. Second, the restriction of our study to only the perspective of the attending physician may have influenced our findings. As the attending physician may not always be aware of whether palliative care services were involved or whether a patient ever made a euthanasia request to other health professionals, the rate of palliative care service use and euthanasia requests may have been underestimated. Third, the sensitivity of the survey topic may have introduced the possibility of untruthful or socially desirable reporting, but this is likely to be negligible given the explicit guarantee of anonymity.

Considering the prevailing idea that palliative care and euthanasia are incompatible, it is striking that our study found that requests for euthanasia were associated with higher rates of palliative care involvement, irrespective of the patient's sex, age, diagnosis, and place of death. This corroborates previous research in the United Kingdom and the Netherlands.<sup>22,23</sup> Furthermore, reports from Oregon and Washington show that a substantial proportion of people who died by physician-assisted suicide were enrolled in hospice.<sup>24,25</sup> A possible explanation is that physicians want to ensure that all available palliative care options have been considered before granting a request. Furthermore, respecting the patient's wishes, patient autonomy, self-determination, and an emphasis on open communication are key principles of palliative care.<sup>10</sup> This

might encourage people to express their thoughts and wishes, including wishes for a hastened death, while in the care of professionals skilled in palliative care.<sup>22,26</sup> Whatever the underlying reason, our study suggests that in a context of legalized euthanasia, palliative care specialists will often be faced with euthanasia requests.

Moreover, our study found that, at least in Flanders, the involvement of palliative care does not reduce the likelihood that a euthanasia request is granted and people retain their right to end their lives despite being enrolled in palliative care. This finding is at odds with the widely held belief that palliative care will alter most requests for euthanasia.<sup>10</sup> The finding is also congruent with the official viewpoint on euthanasia and palliative care of the Federation of Palliative Care Flanders;<sup>11</sup> Flemish palliative care practice indeed seems to accept the possibility of euthanasia in a palliative care context. Other scholars have previously argued that in Belgian end-of-life care, euthanasia and palliative care practices complement rather than oppose each other.<sup>27,28</sup>

This is further illustrated by the finding that palliative care is often involved in euthanasia procedures, both in consultations about euthanasia requests and in the performance of euthanasia. According to many, this is reasonable and even desirable in a context of legal euthanasia since palliative care professionals are the relevant experts in end-of-life care. Initially, a substantial part of the palliative care community in Belgium was hesitant to become involved in euthanasia practice.<sup>11</sup> However, from a sense of duty and the wish not to abandon patients requesting euthanasia, palliative care professionals became increasingly involved in euthanasia practice by supporting the attending physician in the decision-making process and even in the performance of euthanasia.<sup>11,28,29</sup> In this way, palliative care professionals put into practice their desire to avoid euthanasia being performed outside the familiar care environment and chose to ensure continuity of care.

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

In about one in four people who requested euthanasia and were not referred to palliative care services, the reason for non-referral was that the patient refused it. A previous study conducted in the Netherlands also found that if palliative care was not involved in a case of euthanasia, this was mainly because the patient had refused it.<sup>30</sup> Questions can be raised about whether the legal requirement that the patient's suffering cannot be alleviated can be fulfilled when not all palliative care options have been exhausted. A palliative filter, that is, a compulsory consultation with a

palliative care expert when a person requests euthanasia, could address this concern. However, the option of a palliative care filter was not included in the Belgian euthanasia law because it is a patient's right to refuse treatment, including palliative care treatment, and because of fears that some physicians may use the palliative care filter to delay or defer the decision.

## Conclusion

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

The involvement of palliative care in, and its positive stance toward, euthanasia may be particular to the Belgian situation. However, our study does suggest that health professionals working in palliative care are likely to be confronted frequently with euthanasia requests, regardless of their personal attitudes toward assisting people in dying. With an increasing number of people worldwide having the legal option of medical aid in dying, the question of how palliative care physicians and nurses respond to those requesting euthanasia becomes highly relevant. The experiences from countries with a legal framework for assisted dying are informative to palliative care communities in jurisdictions considering, or in the process of, legalization of euthanasia. These experiences can help to reflect on the reconciliation of traditional palliative care values with the acceptance of a patient's right to access euthanasia.

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## Data management and sharing

Individual data cannot be made fully available due to data protection and privacy restrictions that were made under contract with the Flemish Agency for Care and Health, who collected

the data. These restrictions prohibit the research group from sharing the collected data with others to prevent study participants from being identified. Aggregated Data can be requested from the Flemish Agency (anne.kongs@wvg.vlaanderen.be) after requesting permission from the Privacy Commission (joris.ballet@ksz-bcss.fgov.be).

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### Research ethics and patient consent

Ethical approval was obtained from the Ethical Review Board of the University Hospital of the Vrije Universiteit Brussel (ref no. 143201316288, 8 February 2013). Patients were deceased, and consent was not required. Physicians’ participation was regarded as implicit consent, which was noted in the accompanying letter introducing the study.

### References

1. Van Wesemael Y, Cohen J, Bilsen J, et al. Process and outcomes of euthanasia requests under the Belgian Act on Euthanasia: a nationwide survey. *J Pain Symptom Manage* 2011; 42(5): 721–733.
2. Dierickx S, Deliens L, Cohen J, et al. Comparison of the expression and granting of requests for Euthanasia in Belgium in 2007 vs 2013. *JAMA Intern Med* 2015; 175(10): 1703–1706.
3. Meeussen K, Van Den Block L, Bossuyt N, et al. Dealing with requests for euthanasia: interview study among general practitioners in Belgium. *J Pain Symptom Manage* 2011; 41(6): 1060–1072.
4. Onwuteaka-Philipsen BD, Rurup ML, Pasman HRW, et al. The last phase of life: who requests and who receives euthanasia or physician-assisted suicide? *Med Care* 2010; 48(7): 596–603.
5. Jansen-van der Weide MC, Onwuteaka-Philipsen BD and van der Wal G. Granted, undecided, withdrawn, and refused requests for euthanasia and physician-assisted suicide. *Arch Intern Med* 2005; 165(15): 1698–1704.
6. Dyer O, White C and García Rada A. Assisted dying: law and practice around the world. *BMJ* 2015; 351: h4481.
7. Gamester N and Van den Eynden B. The relationship between palliative care and legalized euthanasia in Belgium. *J Palliat Med* 2009; 12(7): 589–591.
8. Herx L. Physician-assisted death is not palliative care. *Curr Oncol* 2015; 22: 82–83.
9. Materstvedt LJ, Clark D, Ellershaw J, et al. Euthanasia and physician-assisted suicide: a view from an EAPC Ethics Task Force. *Palliat Med* 2003; 17(2): 97–101.179.
10. Radbruch L, Leget CJW, Bahr P, et al. Euthanasia and physician-assisted suicide: a white paper from the European Association for Palliative Care. *Palliat Med* 2015; 30(2): 104–116.
11. Vanden Berghe P, Mullie A, Desmet M, et al. Assisted dying—the current situation in Flanders: euthanasia embedded in palliative care. *Eur J Palliat Care* 2013; 20(6): 266–272.
12. Wet betreffende Palliatieve Zorg [Act on palliative care]. *Belgian Law Gaz* 2002; 26: 28515–28520.
13. Chambaere K and Bernheim JL. Does legal physician-assisted dying impede development of palliative care? The Belgian and Benelux experience. *J Med Ethics* 2015; 41(8): 657–660.
14. Centeno C, Lynch T, Donea O, et al. *Atlas of palliative care in Europe 2013*. Milan: European Association for Palliative Care, 2013.
15. The Belgian Act on euthanasia of May, 28th 2002. *Ethical Perspect* 2002; 9(2–3): 182–188.
16. Chambaere K, Vander Stichele R, Mortier F, et al. Recent trends in euthanasia and other end-of-life practices in Belgium. *N Engl J Med* 2015; 372(12): 1179–1181.
17. Onwuteaka-Philipsen BD, Brinkman-Stoppelenburg A, Penning C, et al. Trends in end-of-life practices before and after the enactment of the euthanasia law in the Netherlands from 1990 to 2010: a repeated cross-sectional survey. *Lancet* 2012; 380(9845): 908–915.
18. van der Heide A, Deliens L, Faisst K, et al. End-of-life decision-making in six European countries: descriptive study. *Lancet* 2003; 362(9381): 345–350.
19. Beernaert K, Deliens L, Pardon K, et al. What are physicians’ reasons for not referring people with life-limiting illnesses to specialist palliative care services? A nationwide survey. *PLoS ONE* 2015; 10(9): e0137251.
20. Robijn L, Cohen J, Rietjens J, et al. Trends in continuous deep sedation until death between 2007 and 2013: a repeated nationwide survey. *PLoS ONE* 2016; 11(6): 1–11.
21. Smets T, Bilsen J, Cohen J, et al. The medical practice of euthanasia in Belgium and The Netherlands: legal notification, control and evaluation procedures. *Health Policy* 2009; 90(2–3): 181–187.
22. Seale C and Addington-Hall J. Euthanasia: the role of good care. *Soc Sci Med* 1995; 40(5): 581–587.
23. Brinkman-Stoppelenburg A, Onwuteaka-Philipsen BD and van der Heide A. Involvement of supportive care professionals in patient care in the last month of life. *Support Care Cancer* 2015; 23(10): 2899–906, <http://www.ncbi.nlm.nih.gov/pubmed/25733001> (accessed 27 June 2017).
24. Washington State Department of Health. Death with Dignity Act reports, 2009–2015, <http://www.doh.wa.gov/Youand>



- YourFamily/IllnessandDisease/DeathwithDignityAct (accessed 27 June 2017).
25. Oregon Public Health Division. Oregon Death with Dignity Act: annual reports, 1998–2016, <https://www.deathwithdignity.org/oregon-death-with-dignity-act-annual-reports/>
  26. Van den Block L, Deschepper R, Bilsen J, et al. Euthanasia and other end of life decisions and care provided in final three months of life: nationwide retrospective study in Belgium. *BMJ* 2009; 339: b2772.
  27. Bernheim JL, Deschepper R, Distelmans W, et al. Development of palliative care and legalisation of euthanasia : antagonism or synergy. *BMJ* 2008; 336: 864–867.
  28. Bernheim JL, Distelmans W, Mullie A, et al. Questions and answers on the Belgian model of integral end-of-life care: experiment? Prototype? *J Bioeth Inq* 2014; 11: 507–529.
  29. Desmet M. Palliative care and euthanasia: enemies, friends or neighbours? *Streeven* 2013; 80(11): 965–979 (in Dutch).
  30. Jansen-van der Weide MC, Onwuteaka-Philipsen BD and van der Wal G. Requests for euthanasia and physician-assisted suicide and the availability and application of palliative options. *Palliat Support Care* 2006; 4(4): 399–406.