

## Assisted dying request assessments by trained consultants

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# Changes in peer consultation practice and its quality among consultants trained in assessing assisted dying requests: a repeated cross-sectional survey, 2008-2019

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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 increase in the number of patients who did not meet the substantive requirements for assisted dying in 2019 compared to 2008 (1-4 patients: 41.1% / 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.

**Conclusions:** 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.

### Key Messages

#### **1. What is already known on this topic**

Peer consultations in the context of assisted dying with trained consultants may improve the practice, and thereby assisted dying practice.

#### **2. What this study adds**

The quality of assessing assisted dying request among trained Life End Information Forum consultants in Belgium has increased between 2008 and 2019.

Several changes in the peer consultations to assess assisted dying request with trained consultants have occurred over time.

### **3. How this study might affect research, practice or policy**

Regular monitoring of peer consultation practice and its quality remains important to safeguard assisted dying practice.

Our findings might aid other jurisdictions where assisted dying has been legalized in tailoring and improving their peer consultation practice in the context of assisted dying

## **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 in Euthanasia Networks’ (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 (see Table 1 for the substantive and procedural requirements of Belgian assisted dying legislation). 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. [6–12] 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.[9,10]

<p><b>Table 1. Substantive and procedural requirements specified in Belgian assisted dying legislation [13]</b></p>
<p><b>Substantive requirements</b></p> <ul style="list-style-type: none"> <li>• The patient must be a legally competent adult, an emancipated minor, or a minor with capacity of discernment. Minors may only receive assisted dying in the case of physical suffering caused by a terminal condition.</li> </ul>

- The patient's request must be voluntary, well-considered, repeated, and may not be the result of any external pressure.
- The patient must be in a state of enduring and unbearable physical or psychological suffering. Moreover, the suffering cannot be alleviated and stems from a serious and incurable condition, caused by a somatic or psychiatric illness or by an accident.
- The attending physician must inform the patient about his/her health condition and prospects.
- The attending physician and patient must conclude that there is no reasonable prospect of improvement in the patient's situation.

**Procedural requirements**

- The attending physician must consult another (second) physician (consultant) before proceeding and a third physician when death is not expected in the foreseeable future.
  - The consultant must be independent of both the attending physician and the patient.
  - The consultant must be informed about the serious and incurable nature of the condition, and the reasons for the request.
  - The consultant must read the patient's medical file and/or records, examine the patient, ascertain that the unbearable suffering cannot be alleviated and make a written report about his/her findings.
- After performing assisted dying, the attending physician must notify the case for review to the Federal Euthanasia Control and Evaluation Committee.

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.

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.[12] 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 longer 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 [4,7,9,10] 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).[12] 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.

### 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**

	<b>2008 (N = 71)</b>	<b>2019 (N=140)</b>	<b>P-value for change between 2008 and 2019†</b>
	<b>%</b>	<b>%</b>	
<b>Sex, Male</b>	67.6	55.7	.104
<b>Age</b>			<b>.006</b>
< 40 years	9.9	25.0	
40 – 59 years	70.4	40.7	
≥ 60 years	19.7	34.3	
<b>Medical speciality</b>			>.999
General practitioner	73.2	72.1	
Other medical specialist‡	26.8	27.9	
<b>Number of years working as a LEIF consultant</b>			*
< 5 years	*	43.6	
5 – 9 years	*	30.8	
10 – 14 years	*	17.1	
≥ 15 years	*	8.5	
<b>Motivation to pursue LEIF Physician Training§</b>			
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	*
<b>Additional end-of-life/palliative care training<sup>§</sup></b>			
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	*
<b>Member of palliative care team</b>	25.4	15.1	.091
<b>Number of incurably ill patients at the end of life cared for in the past year</b>			<b>.001</b>
< 5 patients	52.1	27.0	
5 - 19 patients	32.4	56.2	
≥ 20 patients	15.5	16.8	
<p>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 &lt; .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.</p>			

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

**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*
<b>ATTENDING PHYSICIAN CHARACTERISTICS</b>	%	%	
<b>Medical specialty</b>			.543
General practitioner	80.9	85.0	
Other medical specialist	19.1	15.0	
<b>Attitude towards the assisted dying request</b>			<b>.002</b>
Had not made a final decision on whether or not to grant the request	29.4	54.4	
Had decided to grant the request	63.3	42.7	
Had decided not to grant the request	7.4	2.7	
<b>PATIENT CHARACTERISTICS</b>			
<b>Sex, Male</b>	53.7	43.0	.175
<b>Age</b>			<b>&lt;.001</b>
< 60 years	31.8	13.7	
60 -79 years	59.1	55.7	
≥ 80 years	9.1	30.5	
<b>Main diagnosis</b>			<b>.034‡</b>
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	
<b>Reason(s) for requesting assisted dying§</b>			
Suffering without prospect of improvement	79.4	80.3	>.999
Loss of independence in daily living	29.4	53.8	<b>.002</b>
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	<b>.008</b>
Vomiting	2.9	3.8	>.999
Other reason(s)	5.9	9.1	.585
<b>Most important reason for requesting assisted dying</b>			.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	
<b>OUTCOME OF LEIF CONSULTATION</b>			
<b>Substantive requirements were judged to be met</b>	89.7	85.6	.509
<b>Substantive requirements were judged not to be met because other treatment options had not been sufficiently tried out</b>	4.4	5.3	>.999
<b>Substantive requirements were judged not to be met because there was no unbearable suffering</b>	2.9	2.3	>.999
<b>Substantive requirements were judged not to be met because there was no medically hopeless situation</b>	1.5	2.3	>.999
<b>Substantive requirements were judged not to be met because the request was not voluntary</b>	0.0	0.8	>.999
<b>Substantive requirements were judged not to be met because the request was not well-considered</b>	0.0	1.5	.549

<b>Substantive requirements were judged not to be met because the patient was not legally competent</b>	0.0	1.5	.549
<b>Substantive requirements were judged not to be met because of other reason(s)</b>	2.9	2.3	>.999
<b>Assisted dying was carried out</b>			.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.

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.

### 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 Life End Information Forum (LEIF) consultants' most recent consultation in the context of an assisted dying request in 2008 and 2019**

	2008 (N =68)	2019 (N= 132)	P-value for change between 2008 and 2019 <sup>†</sup>
<b>The LEIF consultant</b>	%	%	
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**	<b>65.0</b>	<b>87.1</b>	<b>.003</b>
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)	<b>12.5</b>	<b>47.7</b>	<b>&lt;.001</b>
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)	<b>5.0</b>	<b>28.0</b>	<b>.002</b>
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**	<b>75.0</b>	<b>87.9</b>	<b>.027</b>
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. [4,7,9,10]  
 \*\*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.[7,10,29,30] 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.

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### 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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## Competing interests

FM teaches in the LEIF training. SV, SD, KC, LD and JC declare no conflict of interest.

## Patient consent for publication

Not required.

## Ethics approval

The Medical Ethics Committee of the Brussels University Hospital approved the study protocol and all study materials (B.U.N. 143201939962; March 24, 2019).

## Provenance and peer review

Not commissioned; externally peer reviewed.

## Data availability statement

Data will be stored in the archive of Vrije Universiteit Brussel and will be shared with third parties only upon reasonable request and upon signing a data user agreement, as these data are covered by the GDPR (restricted access).

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Figure 1: Participant flow chart. A non-response survey was only conducted in the 2019-2020 study.

