

Development of palliative care and legalisation of euthanasia: antagonism or synergy?

Debates about euthanasia often polarise opinion, but **Jan Bernheim and colleagues** describe how in Belgium the two camps grew up side by side to mutual benefit

Although palliative care and legalised euthanasia are both based on the medical and ethical values of patient autonomy and caregiver beneficence and non-maleficence,¹ they are often viewed as antagonistic causes. A popular perception, for instance, is that palliative care is the province of religiously motivated people and the advocacy of euthanasia that of agnostics or atheists.^{2,3} The European Association for Palliative Care has voiced concerns that legalising euthanasia would be the start of a slippery slope resulting in harm to vulnerable patients such as elderly and disabled people and that it would impede the development of palliative care by appearing as an alternative.⁴ Data from the Netherlands and Belgium, where euthanasia is legal, do not provide any evidence of a slippery slope.^{5,6} Here, we focus on the effect of the process of legalisation of euthanasia on palliative care and vice versa by reviewing the published historical, regulatory, and epidemiological evidence in Belgium.

History

Detailed accounts of the development of euthanasia and palliative care in Belgium are available elsewhere,^{7,9} but table 1 gives the main milestones. Palliative care started developing in the early 1980s, at the same time as the drive for the legalisation of euthanasia. By 1999 in Europe, Belgium was second only to the United Kingdom in per capita number of beds for palliative

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Accepted: 3 January 2008

care,¹⁰ in 2007 it ranked third of 52 countries in palliative care resources after Iceland and the UK and in 2002 Belgium became the second country to legalise euthanasia.¹¹⁻¹³

Although the societal debate preceding the passing of the euthanasia legislation was intense, with a few exceptions, it was not acrimonious.^{8,14,15} Advocates of legalisation always supported palliative care and never presented euthanasia as an alternative. The only claim that they disputed was that palliative care can always prevent patients from requesting euthanasia.¹³ Proponents of euthanasia argued that, similar to medical futility, there is also such a thing as palliative futility. Conversely, most opponents of the legalisation of euthanasia conceded that in some cases it is ethically acceptable. Some Catholic palliative care workers accepted the regulation of euthanasia as a lesser evil than clandestine life termination or palliative futility.

The euthanasia law eventually contained several concessions to opponents, including restriction to adults with an incurable disease. The reaction of most opponents was cautious acceptance,⁷ acknowledgment of the legal and ethical clarity it brought, and a wish to further refine the regulations.¹⁶

Joint development

One of the reasons for the overall lack of acrimony was that the two movements developed side by side with

Table 1 | Milestones in the development of palliative care and the legalisation of euthanasia in Belgium

Year	Palliative care	Legalisation of euthanasia
1980	Foundation of Continuing Care Community	—
1982	—	Foundation of Association pour le Droit de Mourir dans la Dignité*
1983	—	Foundation of Recht op Waardig Stervent
1984-1995	—	MPs submit draft euthanasia laws
1985	Founding of first university hospital palliative care unit	—
1988-1990	Founding of 6 palliative home care units	—
1989	Founding of St Jan hospice unit	—
1995	15 regional palliative care networks created	MPs submit draft euthanasia law
1996	No of hospice beds reaches 360	—
1997	First palliative care day care centre	—
1998	—	Report of government advisory panel for bioethics: pluralism of opinions—3 legal options
1999	—	New parliamentary majority submits draft law on euthanasia
2000	—	Publication of first epidemiological study on end of life decisions in Flanders (Belgium)
2001	—	Parliamentary hearings
2002	Parliament passes bill on palliative care	Parliament passes euthanasia bill
2003	Flemish Palliative Care Federation endorses integral palliative care	—

*French language right to die society.

†Dutch language right to die society.



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One of the reasons for the overall lack of acrimony was that the two movements developed side by side with shared workers

shared workers. Two of the founders of Belgium's first palliative care organisation, Continuing Care Community, were advocates of the legalisation of euthanasia (Karel Roelants and JLB). The organisation resulted from joint efforts of British expatriates and staff at the Université Libre de Bruxelles and Vrije Universiteit Brussel, whose faculties had been instrumental in changes such as the promotion of contraception, the legalisation of abortion, and innovations in assisted reproduction.^{17 18} Several early palliative care workers were also active in the two Belgian right to die societies. The model they proposed was encapsulated by the term integral palliative care, in which euthanasia is considered as another option at the end of a palliative care pathway and the patient's preferences come first.^{19 20}

From the late 1980s, the medical and paramedical curriculum at Vrije University included palliative care and euthanasia and students were assigned to attend ward rounds in the St Jan hospice. Conversely, Catholic hospitals occasionally referred patients who requested euthanasia to the Vrije University hospital. The first two chairs of the Flemish Palliative Care Federation were staff at Vrije University, one of whom (WD) was a vocal advocate of the legalisation of euthanasia. Also the first palliative care day care centre in Belgium was created by university staff who were advocates of legalised euthanasia.²¹ LEIFartsen (Life End Information Forum), the network of volunteer doctors who give advice to colleagues who receive euthanasia requests, was created by the palliative care department of Vrije University with the support of the Flemish right to die society. All LEIF physicians and nurses are trained in palliative care.²² Thus right from the start shared staff have ensured connection between palliative care

and euthanasia and urged linking of their objectives. As the societal debate about euthanasia grew, so did provisions for palliative care.

Legislative concomitance

Parliament passed the euthanasia law in 2002 after it rejected several amendments aiming to extend or restrict the law. It stipulated that patients requesting euthanasia must be informed of the possibilities of palliative care, but did not require a palliative care team to be consulted before euthanasia, as the Flemish Palliative Care Federation had wanted.²³ The law was passed together with an act positing "the right to palliative care," perfecting the organisation of palliative care and doubling its public funding. Every hospital had to have a palliative care team, and palliative home care was to be available nationwide.

Parliament also created a Control and Evaluation Commission to which euthanasia cases must be reported and specified that four of its 16 members be palliative care workers (the others including doctors, ethicists and lawyers).²⁴ The then president of the Flemish Palliative Care Federation (WD) was appointed its first co-chair.

Professional response

A few months after the passing of the euthanasia law, the Belgian Medical Disciplinary Board issued joint guidelines for euthanasia and palliative care.²⁵ The guidelines broadly endorsed the law and emphasised the recourse to palliative care before carrying out euthanasia. The Flemish Scientific Association of General Practitioners took a similar position.²⁶

The Flemish Palliative Care Federation, intent on avoiding a schism between palliative care workers, adopted an explicitly pluralistic stance. It stated: "The view of the patient must be determining" and that "Palliative care and euthanasia are neither alternatives nor antagonistic. . . Euthanasia may. . . be part of palliative care. . . Caregivers are fully entitled to ethical limitations, but they must be expected to state these limitations candidly, clearly and above all in due time."²⁷ Thus, the federation was the first professional palliative organisation anywhere to acknowledge integral palliative care, a term also adopted by the Flemish Scientific Association of General Practitioners.²⁶ In 2006 the federation issued a typology of medical end of life decisions with a possible or certain life shortening effect, which included a clear description of the medical acts and conditions for a good death with euthanasia. The common conceptual framework further reduces the risk of disagreements due to semantic differences.

No health professional organisation explicitly opposed the euthanasia law in Belgium. The ethics committee of the national Caritas network of Catholic healthcare institutions (which runs over 70% of Belgian hospitals) drafted a guideline for the application of the euthanasia law.²⁸ The only substantial differences from the law are a restriction to terminally ill patients and mandatory consultation with the local palliative care team.²⁹

Table 2 | Percentage of end of life decisions made by doctors in Belgium according to whether they had postgraduate training in palliative or terminal care, 1998*

	No of non-sudden deaths	Euthanasia and physician assisted suicide (n=25)	Life abbreviation without explicit request (n=60)	Alleviation of pain and symptoms (n=332)	Non-treatment decisions (n=303)	All end of life decisions (n=720)
Trained	747	2.5	5.0	29.7	24.1	61.3
Untrained	482	1.2	4.8	22.8	25.5	54.4
P value†	—	>0.05.	>0.05.	0.008	>0.05	0.016

*Weighted row percentages.

†Significance of difference between trained and untrained doctors tested by χ^2 test

Epidemiological data

One more indication of the importance of palliative care in Belgium as euthanasia received more prominence is that between 2001 and 2005 it had by far the highest per capita participation in conferences of the European Association for Palliative Care, even though none took place in Belgium (figure on bmj.com).³⁰ Further data have come from epidemiological studies.

In the 1998 Belgian population based death certificate study on medical end of life decisions with a possible life shortening effect, the odds ratio for doctors who had been trained in palliative care honouring a patient's request for euthanasia compared with their untrained colleagues was 2.07 (95% confidence interval 0.82 to 5.22; table 2).³¹

A similar study of end of life decisions was conducted in 2001, after a vigorous societal debate about the legalisation of euthanasia and further expansion of palliative care.^{6,32} The overall incidence of end of life decisions did not change between 1998 (39.3%) and 2001 (38.4%), but the incidence of voluntary euthanasia substantially decreased (from 1.1% to 0.3%) as did the administering of drugs with the explicit intention to shorten survival without the patient's explicit request



Topaz, the palliative day care centre of the Vrije Universiteit Hospital, also houses the headquarters of both the Flemish Palliative Care Federation and the Life End Information Forum

(from 3.2% to 1.5%), and symptom control with a life shortening effect (from 5.3% to 2.8%). End of life decisions were more frequently discussed with the patients, their relatives, and nurses. Thus during the developments culminating in the legalisation of euthanasia, Belgian doctors increasingly observed the tenets of palliative care.⁶

Discussion

Within Belgium we found few professional stances contending that palliative care and legalisation of euthanasia are antagonistic,¹⁴ no slippery slope effects,⁶ and no evidence for the concern of the European Association for Palliative Care that the drive to legalise euthanasia would interfere with the development of palliative care.⁴ Rather, there were many indications of reciprocity and synergistic evolution.

Regulatory and professional organisations implicitly or explicitly endorsed or accepted the concept of integral palliative care,²⁵⁻²⁷ which recognises the right of patients to decide that further conventional palliative care is futile and to request and obtain physician assisted death. A substantial proportion of Belgian care givers seem to consider euthanasia as a medical act that, with due prudence, is in line with their commitment to palliative care.³³ Thus, the process of legalisation of euthanasia was ethically, professionally, politically, and financially linked to the development of palliative care.

The fact that Belgium is among the countries with the most developed provisions for palliative care (although there is still substantial need for improvement), and the second country to legalise euthanasia seems to be neither paradoxical nor fortuitous. Shared workers and political reciprocity in a country which has institutionalised cultural, religious, philosophical, and ethical pluralism contributed to positive feedbacks between both developments. Beyond that, the societal debates made clear that most values of palliative care workers and advocates of euthanasia are shared.^{1,19} If Belgium's experience applies elsewhere, advocates of the legalisation of euthanasia have every reason to promote palliative care, and activists for palliative care need not oppose the legalisation of euthanasia.

This study is dedicated to the memory of Henk Pelsers (Amsterdam) and Yvon Kenis (Brussels), humanist physicians. We thank Carlos Centeno-Cortes, Heidi Blumhuber, Etienne De Groot, Ruddy Verbinen, and Léon Favvyts for historical information. Johan Vanoverloop did the statistical calculations. We thank Dina Declerck, Paul Schotsmans, and Bert Vanderhaeghen for critical comments and Jane R Mayes for corrections in the manuscript.

Funding: Supported by Grant No HOA2, Vrije Universiteit Brussel.

Competing interests: None declared.

Contributors and sources: JLB and WD were actors in both the palliative care and legalisation of euthanasia movements and explicit promoters of the synergy idea. AM is the head of the regional palliative care network of Brugge and president of the Flemish Palliative Care Federation. The article is based on historical records, epidemiological studies, regulatory guidelines, scientific and lay press publications by advocates and opponents of the legalisation of euthanasia, and personal experience of the clinicians. We presented our data and arguments at various national and international scientific and professional palliative care meetings including the International Association of Bioethics and the European Association for Palliative Care. JLB took the initiative for this paper, wrote it, and consulted the other authors to improve it. RD, JB, LD provided much of the epidemiological data. JLB is the guarantor.

Provenance and peer review: Not commissioned; externally peer reviewed.

SUMMARY POINTS

Palliative care and legalisation of euthanasia are widely viewed as antagonistic societal developments and causes. Belgium was the second country to legalise euthanasia but also has among the best developed palliative care. Advocates for legalisation of euthanasia worked in palliative care and vice versa. Adequate palliative care made the legalisation of euthanasia ethically and politically acceptable. The development of palliative care and the process of legalisation of euthanasia can be mutually reinforcing.

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Losing our way

Men have better visuospatial abilities than women. They read a map better. But is this difference related to hormones or just because men have a Y chromosome?

In the setting of a gender identity clinic one could investigate this question quite easily, since many of the patients are treated with high doses of cross-sex hormones and can be tested before and after such treatment.

There was a heaven sent opportunity to conduct such a study when the clinic in which I work was to relocate to new premises. All the patients were to be sent a map showing them the new location. The effects of treatment on their visuospatial abilities could be investigated by simply asking them if they got lost trying to find the clinic. It seemed an ideal and unchallenging setting for such a study.

Unchallenging, that is, until the application to the ethics committee had to be completed.

I was asked to describe at length the purpose of the study, to describe

the question I would ask, and to quantify how long I would spend asking it. I was required to get a consent form prepared, to be given to patients before I asked my question.

It seemed that I was supposed to consider the risks attached to asking patients if they got lost, and how I would deal with those risks. In short, I was supposed to inform them that I was about to ask them if they got lost; tell them why I was about to ask them; get them to consider agreeing to be asked; ensure that they knew they did not have to answer my question; require them to fill in a form saying that they agreed to be asked; and then, finally, ask them if they got lost.

The chances of getting an unrehearsed, unconsidered, and thus meaningful answer seemed slim. Another study that fell at the hurdle of ethics application. Shame.

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