



European Association for Palliative Care

Non Governmental Organisation (NGO) recognised by the Council of Europe

Palliative Care Development in Countries with a Euthanasia Law

Report for the Commission on Assisted Dying Briefing Papers
Submitted October 4th, 2011

Co-authored by

**Kenneth Chambera¹, PhD, Carlos Centeno², PhD, Erick Alejandro Hernández²,
MSRTP, Yanna Van Wesemael¹, MA, Francisco Guillén-Grima³, PhD, Luc
Deliens¹, PhD, Sheila Payne⁴, PhD**

¹ *End-of-Life Care Research Group, Ghent University & Vrije Universiteit Brussel, Belgium*

² *Palliative Medicine Department, University of Navarra Clinic, Pamplona, Spain*

³ *Department of Health Sciences, Public University of Navarra, Pamplona, Spain*

⁴ *European Association for Palliative Care (EAPC), President*



**Clínica
Universidad
de Navarra**



Ghent University & Vrije Universiteit Brussel

end-of-life care research group

Table of contents

Introduction.....	3
Comparative analysis of indicators of national palliative care development (7 countries)	5
Aims and method	5
Sources of data	5
Results	6
Discussion	10
References	11
Scientific literature Review	12
The standard of palliative care in jurisdictions that have legalised euthanasia/assisted suicide	12
Change in the standard of palliative care since legalization of euthanasia/assisted suicide	14
How legalized euthanasia/assisted suicide may have affected palliative care development	15
References	17
General conclusion	19

Introduction

The Commission on Assisted Dying has requested the European Association of Palliative Care (EAPC) to deliver a report on the quality of palliative care in those countries that have legalised euthanasia and/or assisted suicide in Europe, namely Belgium, the Netherlands, Luxembourg and Switzerland. More precisely the Commission asked *“to investigate the standard of palliative care in jurisdictions where euthanasia and/or assisted suicide has been legalized and assess whether the standard has changed for better or worse since legalisation and how legalisation of euthanasia and/or assisted suicide may have effected how palliative care has developed in that country.”*

Analysing these questions, we were confronted with a number of limitations. It is difficult to answer them on empirical grounds and with valid and reliable data for all four countries. First of all, most data are limited to Switzerland, Belgium or the Netherlands; we have not found any studies on Luxembourg so this report could not take it into account. Secondly, Switzerland has no legislation on euthanasia and/or assisted suicide. Hence, making an association between the law-making process and the implementation of the law on the one hand, and the development of palliative care on the other, is theoretically impossible. Thirdly, palliative care quality indicators have not been implemented on an international level. Hence, measuring and comparing quality of palliative care across countries is a challenging but almost impossible task at this stage, and standards of care cannot be compared across countries. However, both in the literature and in some international reports, indicators of the development of palliative care have been presented. Hence, this report will rely on those indicators that suggest rather than measure quality of palliative care.

The President of the EAPC commissioned two respected research teams to fulfil the task, the team of Professor Carlos Centeno from the Clínica Universidad de Navarra in Spain (www.unav.es), a country where euthanasia and/or assisted suicide has not been legalized, and the End-of-life Care Research Group of Ghent University and Vrije Universiteit Brussel in Belgium (www.endoflifecare.be), a country where euthanasia has been legalised. The two teams have collaborated on an equal basis but their interpretation of some of the findings has not always been the same. This reflects the different experiences of clinicians and researchers in countries with different models of end-of-life care in different societal contexts, one with and one without legalisation of euthanasia and/or assisted suicide. For many years in science and at conferences we have experienced these societally driven differences. Hence, we could say that in Europe we are not only living in different legislations, with regard to euthanasia and/or assisted suicide, but as a consequence of these differences, health care systems and medical as well as popular culture have become different.

In Belgium and the Netherlands physicians and nurses have been trained and educated in end-of-life care with an euthanasia option and the public and patients have learned to live with the possibilities of euthanasia and/or assisted suicide. In the Netherlands and Belgium clinicians and their patients are experiencing end-of-life care in a more open context than prior to the legalisation of euthanasia and assisted suicide, when these practices were already taking place but were not open to debate in the clinical context; training and inter-vision (supervision between colleagues) were not possible, and neither was open communication with the patients and their families as criminal prosecution could not be excluded.

This report consists of two main sections and conclusions. Section one is a comparative analysis of indicators of national palliative care developments and section two is a review of the relevant literature. The report concludes with a short comment on the presented evidence.

Comparative analysis of indicators of national palliative care development (seven countries)

Aim and Method

In this section we will analyse markers and indicators on the development of palliative care found in recent literature (10 years).

Countries included in the case study are the Netherlands, Belgium and Switzerland; they will be compared with other three European countries: Germany, France and Spain. The UK is considered, as in other studies, as a country of reference rather than of comparison, understanding that it has the greatest degree of palliative care development.

Priority has been given to specific direct indicators (for example, development of palliative care services) and indirect ones (for example, the consumption of morphine per capita or the number of participants in congresses) but not for other less specific indicators (for example the way in which family doctors apply the principles of palliative care or the fraction of GDP dedicated to health).

Sources of data

No prospective studies exist which, with identical methodology, analyse the evolution of development of palliative care or which would allow one to infer conclusively whether legalisation of assisted dying is associated with the greater or lesser promotion of palliative care.

One source of data has been the EAPC Palliative Care Atlas in Europe¹ which was created by using specialists in palliative care previously identified in each country. Through a questionnaire, data and estimates were obtained which were then submitted to a process of peer review by the National Associations of Palliative Care of each country. The working method and results of the EAPC study are available online² and have been used in subsequent publications by other authors³, including in a technical report for the European Parliament⁴ which includes a ranking of the European Union with the methodology explained, and combines the existence of specific services with data on the vitality of the palliative care movement in each country. The other study cited³ is from The Economist and includes a global index (Quality of Death Index), but its method has not been published.

Other sources used have been:

a) the State of Pain Treatment Global Report. Access to Palliative Care as a Human Right⁵.

b) the monograph Assessing Organization to Improve PC in Europe (Ahmedzai, 2010) which cites data obtained from multiple sources from previous years; the data on resources available comes from studies by different authors⁶. It has been used to contrast with data from the EAPC study.

c) references found through consultation of financing or development of palliative care services in the Netherlands⁷⁻⁹ and Belgium¹⁰, providing recent data to contrast with previous sources.

d) the web page of the European Association for Palliative Care (EAPC) for data on the number of participants in general congresses and research congresses in the specialty¹¹.

e) PubMed: bibliometric data have been created from the Medline database for this report to look up references.

f) for the section on other indicators a number of sources have been used. The study "Palliative Care in Western Europe" presented online¹² uses maps to display the comparative performance of 17 countries in Western Europe for a number of variables that are related to palliative care. This study presents data on the consumption of opiate medication derived from WHO data. The data on the prevalence of pain in cancer patients come from a study "European Pain in Cancer" (EPIC) performed in 2007¹³. On the use of different opiates to treat cancer pain, data were obtained from the Cross-Sectional Survey Form of the European Association for Palliative Care Research Network¹⁴. Data on the existence of official accreditation for palliative medicine are from the EAPC study¹⁵.

Results

Specific palliative care resources (Table 1)

The proportion of palliative care beds in the Netherlands and Belgium is greater than in the surrounding countries except the UK. In the Netherlands these beds are mostly found in hospices whereas in Belgium palliative care is organised in hospital palliative care units. The data of the EAPC Atlas can however not be confirmed by Ahmedzai⁶. In Ahmedzai's study, the results were different: fewer palliative care beds in Belgium and the Netherlands than in Germany or Spain.

In the Netherlands, where it has been possible to contrast the data of 2005 with the more recent sources of 2011 (see Note 5 in Table 1) an important development is observed in specific services (especially hospice services) which may have already reached the level of the reference country, the UK, at the present time. There are no recent data on the palliative care resources in Belgium, but the study of the 2008 Federal Evaluation Report shows a 72% increase in federal spending in 2007 over that of 2002 which corresponds mostly, but not entirely, to palliative care provision at home.

Palliative support teams in Dutch hospitals were less numerous in 2005 (and in 2011) than in France and the UK only. The Belgian estimate for this indicator should perhaps be confirmed as it is a very high number, but the fact that by law every Belgian hospital must have a palliative support team can explain this finding. Home care teams have probably developed unevenly across nations: only marginally in the Netherlands, but vigorously in Belgium, Spain and the UK.

Table 1 – Specific resources per million inhabitants as presented in the EAPC Atlas (data of 2005)

	UK	Spain	France	Germany	Netherlands (5)	Belgium (Flanders)	Switzerland
<i>Inpatient Units (PCUnit + hospices) (1)</i>	3,7 (1,1+2,6)	2,2 (2,2+0)	1,3 (1,3+0)	3,0 (1,4+1,6)	5,3 (0,2+5,1)	4,7 (4,7+0)	2,3 (1,6+0,7)
<i>Palliative Care Beds (2)</i>	53,1	25,3	26,6	24,6	43,9	34,8	NA
<i>Palliative Support Teams in Hospital (3)</i>	5,1	0,6	5,1	0,7	3,1	12,4	0,9
<i>Home Care Services (4)</i>	5,9	3,2	1,4	0,4	NA	2,4	1,9
<i>Palliative Care Physician (full time)</i>	7,4	11,3	6,0	NA	0,6	2,3	NA

Notes:

(1) Inpatients units per million inhabitants in 2009/10 (PC Units plus Hospices, data of Jasper G, method unknown, cited in Ahmedzai, 2010): UK: 5,0+4,3=9,3 / Germany: 2,6+4,0=6,6 / the Netherlands: 1,0+3,0=4,0). In 2011 (PC Unit plus any hospice, exact data from Agora 2011): the Netherlands: 1,5+14,9=16,4.

(2) PC beds per million inhabitants in 2009/10 (in PC Units or Hospices, data of Jasper G, method unknown, cited in Ahmedzai, 2010): UK: 58 / Spain: 48 / France: 19 / Germany: 40 / Netherlands: 18 / Belgium: 36.

(3) In 2011(exact data from Agora 2011): the Netherlands: 2,6.

(4) Palliative home care services per million inhabitants in 2009/10 (data of Jasper G, method unknown, cited in Ahmedzai, 2010): UK: 5,2 / Netherlands: 5,7). In 2011(exact data from Agora 2011): the Netherlands: 7,8.

(5) In the Netherlands, a report on the diversity and capacity use of palliative care facilities estimated the number of palliative care facilities in 2004 to be 158 with 619 beds. The number of facilities had grown extensively in the preceding 10 years. According to Agora, the national support centre for palliative care founded in 2002 on the impulse of the Ministry of Health, there are currently 689 palliative care facilities with 1271 places in the Netherlands, ranging from hospice care to volunteer organizations. Also, the number of beds in palliative care facilities increased from 41 per million inhabitants in 2004 to 55 per million inhabitants in 2006. The percentages of deceased persons having used a palliative care service before dying have also increased.

Attendance at EAPC conferences by professionals in palliative care (Fig. 1-2)

In General and Research Conferences of the European Association for Palliative Care (EAPC), the average participation level of Belgium and the Netherlands is higher than the countries of comparison. There is however a slight decline or stabilisation in Belgian participation.

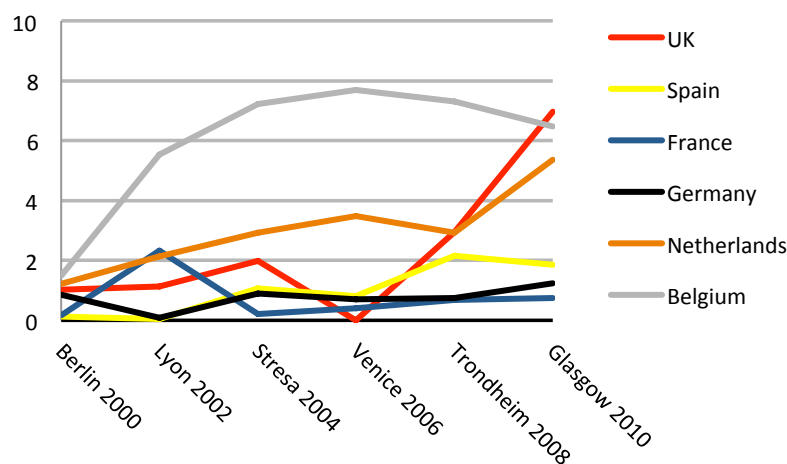
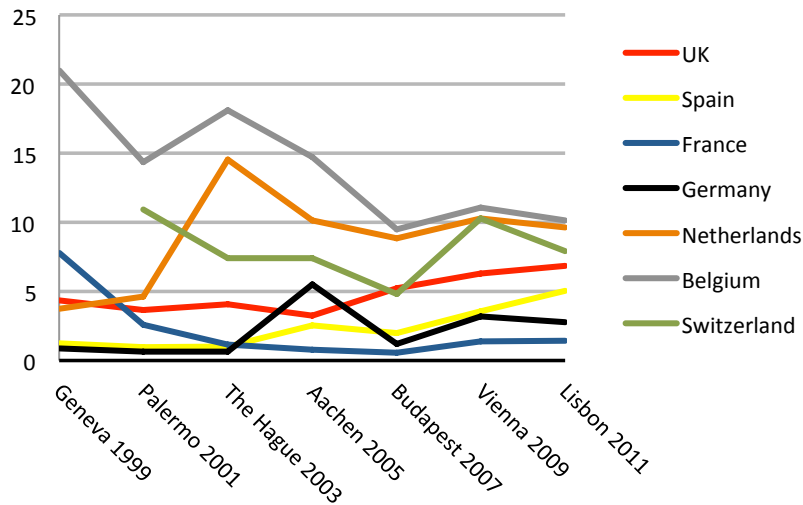
Figure 1 – Participants at EAPC Research Conferences from different countries 2000-2010 (per million inhabitants)

Figure 2 – Participants at EAPC General Conferences from different countries 1999-2011 (per million inhabitants)



Bibliometric parameters related to palliative care literature (Table 2)

There is an increase in the number of research publications that include the words “palliative care” and “hospice care” per million inhabitants. We reached this conclusion by comparing the amount of work indexed in PubMed 10 years after the legalisation of euthanasia and the same period before that date. According to these results, the Netherlands, Belgium and Switzerland are roughly on a par with the reference country the UK. The results are similar in the UK and other countries of comparison. Furthermore, the number of publications after legalisation has kept a similar growth rate for all the countries. We have not investigated the amount of work related to assisted dying exclusively or of those related to both topics together.

Table 2 – Number of PubMed references with the word “palliative care” or “hospice care” (per million inhabitants) up to 2011, before and after legalisation of euthanasia

	UK	Spain	France	Germany	Netherlands	Belgium	Switzerland
<i>Total up to 2011</i>	39,8	8,8	13,7	18,3	55,1	45,0	50,2
<i>2001-2011 (+/- after legalisation)</i>	25,2	5,8	8,0	12,4	32,6	30,2	28,2
<i>1991-2001 (before legalisation)</i>	10,3	2,5	4,6	4,4	18,6	10,3	16,4
<i>Difference before and after legislation</i>	14,9	3,2	3,4	8,0	14,0	19,8	11,8

Other indicators with indirect impact on palliative care development (Table 3)

The ratio of deaths at home varies in the countries analysed. In Belgium and the Netherlands, there are Chairs of palliative care in universities as there are in Germany and the United Kingdom. Incidence of pain and severe pain, opioid consumption and the rate of patients who receive this kind of medication are similar in all countries included in this study. We estimate that almost all patients with pain have access to appropriate treatment in these nations too. Palliative care is considered an official medical specialty in the United Kingdom, and it is a medical subspecialty in France and Germany.

Table 3 – Other indicators related indirectly to the development of palliative care

	No. of sources	UK	Spain	France	Germany	Netherlands	Belgium	Switzerland
Death at home (%)	(6)	18	40	27	30	32	27	NA
Patient with cancer reporting pain (%)	(13)	65	NA	62	NA	NA	NA	75
Cancer patient with severe pain (%)	(13)	23	NA	24	NA	NA	NA	27
Use of opioid medications (mg/year/capita)	(12)	40,1	42,8	57,3	66,1	51,9	40,0	172,0
Prescribing opioid for patients with cancer pain (%)	(14)	86	77	120	123	136	72	80
Availability of opioids	(5)	Good	Good	Good	Good	Good	Good	Good
Chairs in palliative medicine (total)	(6)	9	NA	NA	4	3	1	NA
Official certification for palliative care physician	(15)	Specialty	in process	Sub-specialty	Sub-specialty	none	none	none

Classifications and rankings of palliative care development (Table 4)

In the Clark system, all countries considered in this report section (Belgium, the Netherlands, Switzerland, UK, France, Germany, Spain) are classified with the highest score ie approaching integration of palliative care. The EAPC ranking also puts all these countries in the top ten, with very similar global scores and between 68% and 83% of development relevant to the reference country the UK. Equally, the Economist ranking considers all countries except Spain in high-ranking positions with similar scores.

Table 4 – Global classification or available rankings on palliative care standards

	Reference	Year	UK	Spain	France	Germany	Netherlands	Belgium	Switzerland
Levels of palliative care development	Clark, 2007	2005	#1 of 4	#1 of 4	#1 of 4	#1 of 4	#1 of 4	#1 of 4	#1 of 4
Position in palliative care in EU	Martin Moreno, 2008	2005	#1 of 27	7 of 27	6 of 27	8 of 27	4 of 27	9 of 27	NA
Development relative to UK (%)	Martin Moreno, 2008	2005	-	74	74	70	83	69	NA
Quality of death index	The Economist, 2010	NA	#1 of 40	#26 of 40	#12 of 40	#8 of 40	#7 of 40	#5 of 40	#19 of 40

Discussion

We presented a qualitative and comparative analysis with parameters and indicators of national development in palliative care in seven European countries, three of which have regulated euthanasia and/or assisted suicide and one, the UK, serving as the reference. In this work we cannot detect the influence of the legalisation of assisted dying on the development of palliative care. It could be too soon after the changes in the legislation to be able to observe changes in trends of palliative care development, and future studies may perhaps detect such changes. EAPC is currently re-doing its pan-European survey on development and data will be available in 2012. Surveys of this nature cannot detect any influences the legalisation of assisted dying might have on social, ethical or professional aspects of palliative care practice.

Available data support the idea that in 2005, the Netherlands, Belgium and Switzerland had a similar level of development to other European countries such as Germany, France or Spain. This is shown in the comparative analysis of health parameters and indicators, and can also be concluded from other international studies.

Differences in the levels of availability of some resources, such as palliative care hospital support teams versus hospice care centres, may reflect the different models and conceptions of palliative care in the respective health care systems of the countries analysed, especially in the area of hospice care. The degree of medical specialization of palliative care could be lower in the countries with legalised euthanasia/assisted suicide as there are fewer full time physicians working in palliative care and no official certification of palliative medicine as specialty or subspecialty; however, the interest of professionals in knowledge actualization and research is clearly manifested with a persistently higher per capita attendance at congresses and publications.

The recent data about financing and development of palliative care services in the Netherlands and Belgium obtained through several methods, the comparative bibliometric analysis, and the attendance at EAPC meetings, all show that palliative care has been in continuous development in the last five years. Prospective and comparative transversal studies could confirm these national trends and the influence that legislation of assisted dying may have in this matter.

References

1. Centeno C, et al. EAPC Atlas of Palliative Care in Europe. IAHPC Press. Houston, 2007.
2. EAPC Task Force on the Development of Palliative Care in Europe. Available in <http://www.eapcnet.eu/Themes/Organisation/DevelopmentinEurope/tabid/218/Default.aspx> (accessed September 9th, 2011).
3. Economist Intelligent Unit. The quality of death. Ranking end-of-life care across the world. The economist. Lien foundation. 2010. Available in: http://www.eiu.com/site_info.asp?info_name=qualityofdeath_lienfoundation&page=roads&rf=0 (accessed September 9th, 2011).
4. Martin-Moreno J, Harris M, Gorgojo L, Clark D, Normand C, Centeno C. Palliative Care in the European Union. European Parliament Economic and Scientific Policy Department 2008. IP/A/ENVI/ST/2007-22. PE404.899 [Online]. Available in <http://www.eapc-taskforce-development.eu/tfdocs.php> (accessed September 9th, 2011).
5. Human Rights Watch. Global State of Pain Treatment. Access to Palliative Care as a Human Right. 2011. Available in: <http://www.hrw.org/reports/2011/06/02/global-state-pain-treatment-0> (accessed September 9th, 2011).
6. Ahmedzai S. (ed.) et al. Assessing Organisations to Improve Palliative Care in Europe. Nijmegen, 2010.
7. Mistiaen P, Francke A. Diversity and capacity use of palliative care facilities. [In Dutch] Verscheidenheid en capaciteitsbenutting in palliatieve terminale zorgvoorzieningen. Utrecht: 2004.
8. Palliative care facilities in the Netherlands [Internet]. 2011 [cited 2011 Sep 1]; Available from: <http://www.agora.nl/ZorgKiezen/Perprovincie/tabid/2209/Default.aspx>
9. Mistiaen P, van Ruth L, Francke A. Monitor Palliative Care. Report of 2006 and findings of three years monitor. [In Dutch] Monitor Palliatieve Zorg. Rapport 2006 en bevindingen over drie jaar monitor. Utrecht: 2006.
10. Federal Evaluation Cell on Palliative Care. Evaluation Report Palliative Care 2008. Brussels: Federal Government Department Public Health, Food Safety and Environment, DG Organisation Health Care Services, Cell Chronic, Elderly and Palliative Care, 2008. http://mailsystem.palliatief.be/accounts/15/attachments/rapporten/fed_evaluatiecel_mai_2008_rapport_2008_nl.pdf
11. EAPC web site. Available in <http://www.eapcnet.eu/Corporate/Events/Participantsbreakdown/MainCongresses/tabid/1652/Default.aspx> (accessed September 9th, 2011).
12. Hoefler J. Palliative Care in Western Europe. Available in <http://blogs.dickinson.edu/pceurope/> (accessed September 9th, 2011).
13. Research International (Independent market research company). European Pain in Cancer survey: a report (EPIC). London, 2007. Available in http://www.paineurope.com/fileadmin/user_upload/Issues/EPIC_Survey/EPIC_Report_Final.pdf (accessed September 9th, 2011).
14. Klepstad P, Kaasa S, Cherny N, Hanks G, de Conno F; Research Steering Committee of the EAPC. Pain and pain treatments in European palliative care units. A cross sectional survey from the European Association for Palliative Care Research Network. Palliat Med. 2005 Sep;19(6):477-84.
15. Centeno C, Noguera A, Lynch T, Clark D. Official certification of doctors working in palliative medicine in Europe: data from an EAPC study in 52 European countries. Palliative Medicine 2007; 21: 683-687.

Scientific Literature Review

Though some form of physician-assisted dying is legal in four European countries (Belgium, the Netherlands, Luxembourg and Switzerland), this literature review focuses only on Belgium and the Netherlands. Luxembourg has only recently (2009) legalised euthanasia and assisted suicide, and in Switzerland euthanasia is not legal. Belgium and the Netherlands have also produced ample scientific research into end-of-life issues, as a result largely of the intense focus there has been before and after legalisation. However, little of this research focuses strictly on the quality or standard of palliative care, how well it has developed, and the effects that the legalisation of euthanasia has had on its development. In what follows an overview is given of relevant research results which can be used to form a basic idea about the current (or rather last measured) situation in palliative care development in the Low Countries. They must be treated with caution however, as they are indirect evidence at most, and were not in most cases designed to answer these questions. Moreover, the delivery of palliative care is difficult to measure anywhere because of the variety of delivery mechanisms.

The standard of palliative care in jurisdictions that have legalised euthanasia/assisted suicide

The Belgian legislature passed a law on palliative care parallel to the euthanasia law in 2002. This law states that every patient has the right to palliative care and provides a framework for its further development. In the Netherlands no such law was passed.

Indications of the standard of palliative care can be deduced through key actor consultation, opinion surveys, and even conference attendance records. Fortunately there are also some representative population-based surveys which have gauged the degree of palliative care service involvement at the end of life. For a systematic overview of national and structural indicators of palliative care development, see the section *Indicators*.

Piers et al inquired about the general availability of palliative care for geriatric patients in 21 European countries by surveying key actors in palliative care in each country (survey in 2009)¹. This research shows that both Belgium and the Netherlands are among the countries with the best availability, though the authors could not quantify the results. Importantly, what also emerged from this study is that the organization of palliative care is different in every country and therefore difficult to compare generally.

A 2007 EAPC Task Force study found that Belgium and the Netherlands both had significantly developed palliative care services and had national palliative care associations². According to the authors these associations serve as a catalyzing factor for and promoter of further palliative care development.

Lynch et al identified the barriers to palliative care development in Europe by surveying key actors in each country (survey in 2005)³. In Belgium a lack of training, limited knowledge of opioids (including the myth of lethality of morphine), limited funding and insufficient professionally-based organization were identified as important barriers to further growth. In the Netherlands a lack of awareness,

limited knowledge of opioids, limited funding, and a lack of coordination were the main factors inhibiting palliative care development. One should keep in mind here that the key actors of other countries also identified numerous barriers to palliative care development in their countries.

Georges et al surveyed Dutch physicians on their opinions on the state of palliative care in the Netherlands in 2001-2003⁴; 30% of physicians agreed with the assertion that palliative care is suboptimal, while 50% disagreed.

Bernheim & Mullie found that Belgian and Dutch attendance (calculated as participants/year/million inhabitants) at EAPC conferences since 2002 ranks 1st (12) and 3rd (8) respectively⁵.

Van den Block et al surveyed Belgian GPs who reported on all deceased patients in their practice in 2005 through a sentinel network⁶. The study found that specialized multidisciplinary palliative care teams were involved in 41% of all non-sudden deaths and in 61% of cancer deaths compared with 25% of non-cancer deaths. In all deaths, palliative care teams were involved only in the last week in 21% of cases and palliative treatment was reported in 44% in the last two to three months, 58% in the last month and 81% in the last week before death. In an analysis of 2007 using the same method, Meeussen et al found that specialized palliative care services had been used in 38% of all non-sudden Belgian deaths, but some form of palliative treatment had been provided in the last week in 77%⁷. These figures for the Netherlands in 2007 are 32% and 91% respectively. Abarshi et al further compared Belgium and the Netherlands and found that palliative treatment goals in the last week were 100% in the Netherlands and 85% in Belgium, while palliative care services were used in the final three months in 38% of deaths at home and 9% in care homes in the Netherlands, and 51% and 34% in Belgium. In the Netherlands GPs are the primary caregivers for palliative care including in care homes, while in Belgium palliative care is provided mainly by specialized palliative care teams, which explains the large differences in these figures⁸.

One other relevant result from the abovementioned survey method is that Meeussen et al found that palliative care in Belgium focuses above all on the physical and less so on the psychosocial or existential issues of the dying. The authors add that this imbalance is not specific to Belgium but is found in most countries⁹.

In a retrospective survey of physicians signing a representative sample of Brussels death certificates in 2007, Cohen et al found palliative care involvement in 23.1% of all non-sudden deaths and 50.3% in cancer deaths. Palliative care was mostly provided at home but almost never in care homes. The low prevalence of palliative care involvement is, according to the authors, due to the constraining metropolitan issues (teaching hospitals with the propensity for aggressive treatment, weak GP involvement in end-of-life care, social fragmentation, barriers to home care, accommodation issues etc.)¹⁰.

Smets et al conducted a representative survey of Belgian physicians in 2009 and found that 48.1% had had some form of training in palliative care (14.5% in basic training, 41% in continuing education or postgraduate course, 5% in other training programmes)¹¹.

Pereira remarks that involvement of palliative care is one thing, but the degree of expertise and experience is another. He feels that the lack of formal training and recognition of palliative care as a medical sub-discipline in both Belgium and the Netherlands, contrary to countries like the UK,

Australia and USA, may indicate undeveloped palliative care because “...the development of expertise in palliative care, as in any other specialty, requires a considerable amount of time”¹². According to Centeno et al, in 2007 the only European countries recognizing palliative care as a sub-discipline are the UK, France and Germany¹³. While we found no data in PubMed on the extent of palliative care expertise or experience of Belgian and Dutch physicians, a 2007 EU report by Martin-Moreno et al found a lack of standardized palliative care training in Belgium but numerous training courses in the Netherlands¹⁴.

Change in the standard of palliative care since legalization of euthanasia/assisted suicide

There is even less evidence to go on in the scientific literature regarding the question of the change in standard of palliative care in Belgium and the Netherlands since legalisation. Most evidence is narrative in nature.

Bernheim et al observed that the Belgian Palliative Care Act passed in 2002¹⁵ has boosted palliative care development and improved palliative care practice⁵. The act stipulated the right of every patient to palliative care, nationwide coverage of palliative care and regulations for an efficient national organization, and, importantly, the doubling of public funds allocated to palliative care. According to the authors, palliative care in Belgium has come a long way since the enactment of the palliative care law (and hence since the legalisation of euthanasia) though they admit that more progress needs to be made⁵. Van den Block et al corroborate this viewpoint¹⁶. Even critics of the legalisation of euthanasia who argue that it will lead to the underdevelopment of palliative care admit that Belgian palliative care “...has experienced significant growth in recent years...”¹⁷.

There is some empirical evidence of the growth of palliative care in Belgium and the Netherlands, albeit again indirect.

Houttekier et al studied trends in place of death in Flanders and Brussels and found that people die more often in care home as more and more skilled nursing beds are created: in 1998 there were 22.8 beds per 1,000 people aged 65 or older, whereas in 2007 this had risen to 29. Skilled nursing beds (with more palliative expertise) have replaced conventional residential beds in care homes, which according to the authors is an indicator and effect of palliative care development in care home settings¹⁸.

In a retrospective survey based on physicians certifying a representative sample of death certificates, Bilsen et al and Chambaere et al found that the intensified alleviation of pain and other symptoms at the end of life had risen strongly in Flanders from 18.4% of all deaths in 1998 and 22.0% in 2001 to 26.7% in 2007^{19,20}. The rise was most significant in non-cancer patients, as the rate in cancer patients stagnated at 45% in 2007²⁰. In the Netherlands a similar rise was found from 18.8% (1990), 19.1% (1995) and 20.1% (2001) to 24.7% (2005)²¹. This can be viewed as a firm indication of increased palliative care provision at the end of life in both countries.

How legalized euthanasia/assisted suicide may have affected palliative care development

The relationship between legal euthanasia/assisted suicide and palliative care development is heavily discussed in scientific literature. However, here again the discourse is mainly argumentative, ethical and value-laden. Nonetheless, there are some results that can be interpreted to clarify this relationship. When reviewing the available papers, the picture emerges of a more complex relationship between euthanasia/assisted suicide and palliative care than merely euthanasia/assisted suicide affecting palliative care.

First a preliminary note. In Belgium and the Netherlands since legalization euthanasia/assisted suicide occurs in 1.9% and 1.7% of all deaths respectively¹⁹⁻²¹. With such low percentages it is difficult to imagine that the impact of legalized euthanasia/assisted suicide on the development of palliative care is significant. Euthanasia/assisted suicide occurs particularly in cancer patients, who also receive the most palliative care. Prevalence in these patients is 5.7% in Belgium²⁰ and 5.1% in the Netherlands²¹, but again not notably high enough to have a substantial potential impact on palliative care development in terms of actual number of patients not receiving palliative care (also, many patients receiving euthanasia had followed a palliative care trajectory). As for other end-of-life decisions such as life-ending without request and non-treatment decisions thought to have risen due to ethical “loosening” following legalization – a supposed indirect effect of euthanasia/assisted suicide legalization –, we can say that these rates have not risen since legalization, both in Belgium and the Netherlands¹⁹⁻²¹.

Deliens & Bernheim suggest that since euthanasia/assisted suicide legalization the focus of the euthanasia debate has moved from an ethical and ideological argument towards the development of the requirements of prudent practice and of guidelines for good medical practice at the end of life²². Palliative care has had a period of significant growth in the Low Countries as a consequence. Gamester & Van den Eynden however rightly warn about attributing this to what is possibly a coincidental association: “while it may be fair to acknowledge that Belgian palliative medicine has experienced significant growth in recent years, it cannot be argued that this is the result of legalization of euthanasia in that country. Similar growth of palliative care services has occurred in other Western European countries,[...], none of which have legalized euthanasia.”¹⁷.

On the other hand, there is scant evidence of the supposed underdevelopment of palliative care. Smets et al’s 2009 representative survey of Belgian physicians revealed that only 10% agree with the assertion that the euthanasia law impedes further development of palliative care in Belgium, and that percentage is lower for physicians trained in palliative care¹¹. Gordijn & Janssens assert that palliative care underdevelopment related to euthanasia/assisted suicide legalization is fairly speculative and lacking a sound empirical basis²³. In a further publication they express the opinion that the history of palliative care development before and after legalisation of euthanasia/assisted suicide in the Netherlands (where euthanasia/assisted suicide was already condoned before legalisation) contradicts fears of underdevelopment²⁴.

What emerges from most of the literature is that palliative care and euthanasia/assisted suicide are closely intertwined. In their 2008 publication, Bernheim et al reject the premise that euthanasia/assisted suicide and palliative care were mutually exclusive movements in Belgium; their history and development has been synergistic, the two movements developed side by side with shared workers²⁵ and the advocates of legal euthanasia have been amongst the strongest supporters

of palliative care⁵. Euthanasia/assisted suicide and palliative care are bound together in legislation and regulations: the Belgian euthanasia law stipulates that all palliative options must be disclosed to the patient²⁶; the Belgian Medical Disciplinary Board stresses the need for recourse to palliative care first when a patient requests euthanasia²⁷, and many institutes demand the mandatory consultation of a palliative care team when euthanasia is requested (the palliative filter in euthanasia)²⁸. And indeed, in medical practice palliative care workers are often involved at some stage of euthanasia/assisted suicide in Belgium; in 2007 palliative care specialists were consulted in half of all euthanasia/assisted suicide cases²⁹. Having received training in palliative care is also associated with higher chances of performing euthanasia^{11,30}. Palliative care service use is further associated with more decisions to explicitly shorten life and – as in Oregon, where most AS patients were enrolled in palliative care hospices³¹ – the highest prevalence of euthanasia/assisted suicide is found in PCUs¹⁶. Based on this, it is asserted that palliative care helps patients express their wishes for the end of life and euthanasia/assisted suicide, and that euthanasia/assisted suicide and palliative care seem to reinforce each other rather than to compete¹⁶. Also in the Netherlands there is evidence that euthanasia/assisted suicide is related to the higher use of palliative care³².

Some argue however that practicing euthanasia/assisted suicide in a palliative care setting is undesirable, as intentionally hastening death is contrary to palliative care philosophy and sends a mixed message to the outside world³³⁻³⁵. Pereira et al on the other hand concede that the advantage of euthanasia/assisted suicide in palliative care settings is that the special care provided to patients requesting euthanasia/assisted suicide “could result in them rescinding their original requests”³³. In the Netherlands there is some potential evidence: euthanasia/assisted suicide decreased between 2001 (2.5%) and 2005 (1.7%), which is hypothesised to be because of increased palliative sedation, or more generally development of palliative care provision and techniques²¹. In Belgium the rate rose from 1.1% in 1998 to 1.9% in 2007, but this is mainly due to its illegality in 1998²⁰. The euthanasia/assisted suicide rate is at the same level as in the Netherlands and palliative sedation also occurs frequently which could indicate a similar degree of euthanasia/assisted suicide substitution by palliative sedation³⁶.

From this it could be argued that euthanasia requests stem from a lack of adequate palliative care and that euthanasia will be more prevalent in jurisdictions where palliative care is less well developed²⁴. This could be argued to mean that euthanasia/assisted suicide need not be legalized as long as optimal palliative care can be delivered. However, there is much research which suggests that palliative care does not systematically prevent euthanasia/assisted suicide requests^{4,5,16,25,30,37-40}, as there is such a thing as palliative futility²⁵ and some of the most important reasons for euthanasia/assisted suicide requests, being psychosocial and existential in nature (such as dependency, hopelessness, loss of dignity, degeneration and depression) and even refractory pain cannot always be dissipated by palliative care^{12,16,30,40-42}.

References

1. Piers et al. Palliative care for the geriatric patient in Europe. *Z Gerontol Geriat* 2010, 43:381-385.
2. Centeno et al. Facts and indicators on palliative care development in 52 countries of the WHO European region: results of an EAPC task force. *Pall Med* 2007, 21:463-471.
3. Lynch et al. Barriers to the development of palliative care in Western Europe. *Pall Med* 2010, 24(8):812-819.
4. Georges et al. Physicians' opinions on palliative care and euthanasia in the Netherlands. *J Pall Med* 2006, 9(5):1137-1144.
5. Bernheim & Mullie. Euthanasia and palliative care in Belgium: legitimate concerns and unsubstantiated grievances. *J Pall Med* 2010, 13(7):798-799.
6. Van den Block et al. Care of patients in the last months of life. The Belgian sentinel network monitoring end-of-life care study. *Arch Intern Med* 2008, 168(16):1747-1754.
7. Meeussen et al. Advance care planning in Belgium and the Netherlands: a nationwide retrospective study via sentinel networks of general practitioners. *J Pain Symptom Manage* 2011 (in press).
8. Abarshi et al. Use of palliative care services and general practitioner visits at the end of life in the Netherlands and Belgium. *J Pain Symptom Manage* 2011, 41(2):436-448.
9. Meeussen et al. Dealing with requests for euthanasia. Interview study among general practitioners in Belgium. *J Pain Symptom Manage* 2011 (in press).
10. Cohen et al. The use of palliative care services associated with better dying circumstances. Results from an epidemiological population-based study in the Brussels Metropolitan Region. *J Pain Symptom Manage* 2011 (in press).
11. Smets et al. Attitudes and experiences of Belgian physicians regarding euthanasia practice and the euthanasia law. *J Pain Symptom Manage* 2011 (in press).
12. Pereira. Legalising euthanasia or assisted suicide: the illusion of safeguards and controls. *Curr Oncol* 2011, 18(2):e38-45.
13. Centeno et al. Official certification of doctors working in palliative medicine in Europe: data from an EAPC study in 52 European countries. *Pall Med* 2007, 21:683-687.
14. Martin-Moreno et al. Policy Department Economic and Scientific Policy. Palliative Care in the European Union. Brussels, 2008.
15. Belgian official collection of the laws 2002022868 (2002). [Law concerning palliative care] (Dutch).
16. Van den Block 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.
17. Gamester & Van den Eynden. The relationship between palliative care and legalised euthanasia in Belgium. *J Pall Med* 2009, 12(7):589-590.
18. Houttekier et al. Study of recent and future trends in place of death in Belgium using death certificate data: a shift from hospitals to care homes. *BMC Public Health* 2011, 11:228.
19. Bilsen et al. End-of-life practices under the euthanasia law in Belgium. *NEJM* 2009, 361(11):1119-1121.
20. Chambaere et al. Trends in medical end-of-life decision making in Flanders, Belgium 1998-2001-2007. *Med Decis Making* 2010, epub ahead of print.
21. van der Heide et al. End-of-life practices in the Netherlands under the euthanasia act. *NEJM* 2007, 356(19):1957-1965.
22. Deliens & Bernheim. Palliative care and euthanasia in countries with a law on euthanasia. *Pall Med* 2003, 17:393-394.
23. Gordijn & Janssens. The prevention of euthanasia through palliative care: new developments in the Netherlands. *Pat Educ Couns* 2000, 41:35-46.
24. Gordijn & Janssens. Euthanasia and palliative care in the Netherlands: an analysis of the latest developments. *Health Care Analysis* 2004, 12(3):195-207.
25. Bernheim et al. Development of palliative care and legalization of euthanasia: antagonism or synergy? *BMJ* 2008, 336: 865-867.
26. Belgian official collection of the laws 2002009590 (2002). [Law concerning euthanasia] (Dutch).
27. Belgian Medical Disciplinary Board (2003). [Recommendation on palliative care, euthanasia and other end-of-life decisions] (Dutch).
28. Schotsmans & Gastmans. How to deal with euthanasia requests: a palliative filter procedure. *Camb Q Healthcare Ethics* 2009, 18:420-428.

29. Chambaere et al. Physician-assisted deaths under the euthanasia law in Belgium: a population-based survey. *CMAJ* 2010, 182(9):895-901..
30. Van Wesemael et al. Process and outcomes of euthanasia requests in Belgium under the euthanasia act: a nationwide survey. *J Pain Symptom Manage* 2011, epub ahead of print.
31. Quill. Legal regulation of physician-assisted death – the latest report cards. *NEJM* 2007, 356:1911-1913.
32. Onwuteaka-Philipsen et al. The last phase of life: who requests and who receives euthanasia or physician-assisted suicide. *Med Care* 2010, 48(7):596-603.
33. Pereira et al. Assisted suicide and euthanasia should not be practised in palliative care units. *J Pall Care* 2008, 11(8):1074-1076.
34. Matersvedt et al. Euthanasia and physician-assisted suicide: a view from an EAPC Ethics Task Force. *Pall Med* 2003, 17:97-101.
35. Sepulveda et al. Palliative care: the World Health Organisation's global perspective. *J Pain Symptom Manage* 2002, 24:91-96.
36. Chambaere et al. Continuous deep sedation until death in Belgium: a nationwide survey. *Arch Intern Med* 2010, 170(5):490-493.
37. Jansen-van der Weide et al. Requests for euthanasia and physician-assisted suicide and the availability and application of palliative options. *Palliat Support Care* 2006, 4(4):399-406.
38. Verpoort et al. Palliative care nurses' views on euthanasia. *J Adv Nursing* 2004, 47(6):592-600.
39. Gielen et al. Flemish palliative care nurses' attitudes toward euthanasia: a quantitative study. *Int J Pall Nursing* 2009, 15(10):488-497.
40. Maessen et al. Requests for euthanasia: origin of suffering in ALS, heart failure, and cancer patients. *J Neurol* 2010, 257(7):1192-1198.
41. Smets et al. Legal euthanasia in Belgium. Characteristics of all reported cases. *Med Care* 2010, 48(2):187-192.
42. Georges et al. Differences between terminally ill cancer patients who died after euthanasia had been performed and terminally ill cancer patients who did not request euthanasia. *Pall Med* 2005, 19:578-586.

General conclusion

This report has shown that palliative care is well developed in countries with legalised euthanasia/assisted suicide, or at least no less well developed than in other European countries. Though international comparison is difficult given the differences in organisation and structure of palliative care provision, these countries (Belgium, the Netherlands, Luxembourg and Switzerland) rank high in Europe for most structural or national indicators. The literature review confirmed a degree of palliative care provision in Belgium and the Netherlands that is comparable with surrounding countries but, as in any other country, there are still some important improvements to be implemented.

There is evidence of advancement of palliative care in countries with legalised euthanasia, also after the legalisation of euthanasia and/or assisted suicide. The idea that legalisation of euthanasia and/or assisted suicide might obstruct or halt palliative care development thus seems unwarranted and is only expressed in commentaries rather than demonstrated by empirical evidence. But we must also consider that it has only been a short period of time – less than 10 years – after legalisation of euthanasia and/or assisted suicide and changes in trends for complex social issues such as this one may only become apparent after a longer period.

The European Association for Palliative Care (EAPC) formulated a position on euthanasia and assisted suicide published in 2003 which recognised the diversity of views and perspectives across the cultures and traditions that make up European nations. Ten position statements were proposed. This report adds to this work by carefully reviewing and presenting the evidence. We recommend that it is essential that nations who are considering legalising euthanasia or assisted suicide establish equitable, accessible and affordable palliative care and ensure a broad national structure for the provision of palliative care services.