



State of Palliative Care Development in European Countries with and without Legally Regulated Physician-Assisted Dying

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Abstract - In 2002 physician-assisted dying was legally regulated in the Netherlands and Belgium. Besides fundamental and ethical objections to physician-assisted dying, one of the frequently expressed pragmatic concerns is that legal regulation of physician-assisted dying, as implemented in the Netherlands and Belgium, could stunt the development of palliative care and erode its culture of competent and compassionate care. We here review these controversies and test the hypothesis that legal physician-assisted dying impeded the development of palliative care in the Netherlands and Belgium.

We collected the data over time on the funding of palliative care in Belgium. Next, using the data of the European Association for Palliative Care's 2007 Atlas of Palliative Care, we compared the state of development of palliative care in Western-European countries with and without legally regulated physician-assisted dying.

In Belgium, government expenditure for palliative care grew consistently by a yearly average of 10% over the 5 years following legal regulation of physician-assisted dying. As assessed in 2005, palliative care development in the Netherlands and Belgium did not lag behind Western-European countries without legally regulated physician-assisted dying, and was close to on a par with the UK, the benchmark country.

In conclusion, the hypothesis that legal regulation of physician-assisted dying stunts the development of palliative care is not supported by the Belgian and Dutch experience of the first several years. Continued monitoring of both permissive and non-permissive countries is needed to assess possible longer-term effects.

Keywords - Development of palliative care, jurisdictions with and without legal physician-assisted dying, the Netherlands, Belgium, European countries.

1. Introduction

Short review of the controversies raised by the Benelux countries' end-of-life legislations

Physician-assisted dying, i.e. physician-assisted suicide and euthanasia, the latter defined as ending a person's life at their explicit request, is in Europe legally regulated only in Belgium and the Netherlands since 2002 and Luxembourg since 2009. The legal conditions of prudence include an explicit and repeated request by a competent adult patient whose physical or mental suffering by an irreversible medical condition is "unbearable" and without any perspective of improvement. Also procedural precautions, including independent peer consultation, must be observed and cases must be reported to a review commission (Deliens & van der Wal, 2003). The experience of the Benelux countries is under intense scrutiny, all the more because legally regulating physician-assisted dying is being debated in several other countries.

Can palliative care and physician-assisted dying be complementary, as posited for the Belgian model of end-of-life care (Bernheim, Deschepper, Distelmans, Mullie, Bilsen, & Deliens, 2008), or are they incompatible? Several recent publications take the latter position, specifically challenging the Belgian construct of 'integral palliative care' and arguing that physician-assisted dying and palliative care are fundamentally antagonistic causes (Jaspers, Müller-Busch & Nauck, 2009; Kettler & Nauck, 2010; Johnstone, 2012; Materstvedt, 2012). The principled rejection of 'integral palliative care' is in line with traditional views in mainstream palliative care (Roy & Rapin, 1994; Hamel, 1998; Mast, Salama, Silverman, & Arnold, 2004; Meisel, 2005; Stephenson, 2006; Bosshard, Broeckaert, Clark, Materstvedt, Gordijn & Müller-Busch, 2008). Indeed, the prevention of physician-assisted dying was one of the prime motivations of the founders of the palliative care movement (Saunders, 1976) and this tenet has remained widely endorsed ever since (Gordijn & Janssens, 2000;

Müller-Busch, Oduncu, Woskanjan, & Klaschik, 2004).

Over and beyond such fundamental ethical stances, also pragmatic objections to legally regulated physician-assisted dying are frequently expressed, including the risks of slippery-slope effects and of erosion of public confidence in the healthcare services (Materstvedt et al., 2003; Finlay, Wheatley & Izdebski, 2005; Gamester & Van den Eynden, 2009; Pereira, 2011). The debate on these practical issues is ongoing. Epidemiological data from Oregon, the Netherlands and Belgium tend to allay these fears (Quill, 2007; Battin, van der Heide, Ganzini, van der Wal, & Onwuteaka-Philipsen, 2007; Bernheim & Mullie, 2010; Chambaere, Bilsen, Cohen, Onwuteaka-Philipsen, Mortier, & Deliens, 2010, 2011; Downie, Chambaere & Bernheim, 2012; Rietjens, Deschepper, Pasmán, & Deliens, 2012). While the epidemiological study results are hardly disputed, there are expressions of scepticism as to the validity of conclusions (Materstvedt, 2009) and criticisms of the imperfections in the enforcement of the Belgian law's prescriptions of prudence (Cohen-Almagor, 2013).

We here focus on a related, intellectually legitimate, pragmatic concern: the oft-invoked fear that legally regulated physician-assisted dying would impede the development of palliative care. This could happen if legally regulating physi-

cian-assisted dying would erode the competent and compassionate care culture of palliative care, reduce demand for palliative care, draw attention and efforts away from palliative care and if governments would be tempted to save on scarce health-care resources by neglecting palliative care, thus nudging citizens and physicians towards the quick fix of physician-assisted dying (Saunders, 1976; Gordijn & Janssens, 2000; Materstvedt et al., 2003; Finlay, Wheatley & Izdebski, 2005; Gamester & Van den Eynden, 2009; Pereira, 2011; Johnstone, 2012).

2. Methods

The hypothesis that legal regulation of physician-assisted dying could stunt the financial support of palliative care was investigated by seeking the governmental data on the funding of palliative care. These were found available only for Belgium (source details in the legend of Figure 1). Next, we compared the state of development of palliative care in European countries with and without legally regulated physician-assisted dying according to the indicators provided by the European Association for Palliative Care's Atlas of Palliative Care.

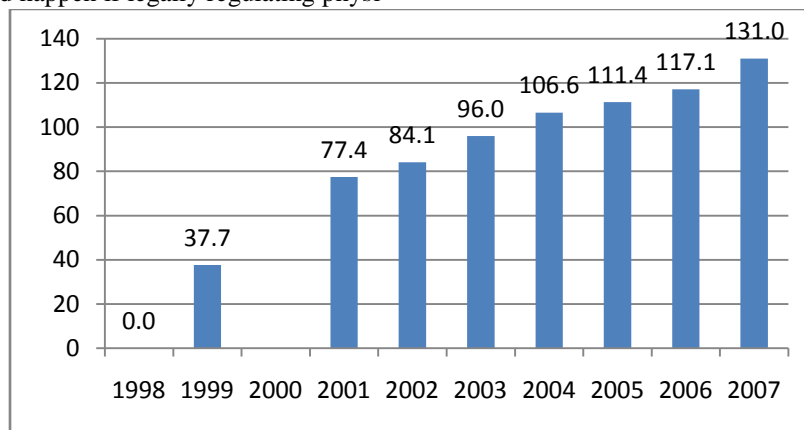


Figure 1. Total national expenditure on palliative care 1998-2007 (in million €)

Source data 1999/2001: press communication by the Federal Secretary for Health in 2001: <http://oud.frankvandenbroucke.be/html/soc/P-011029.htm> (last accessed 13 June 2013), and converted from Belgian francs to Euros with the exchange rate of the introduction of the Euro in Belgium (1 EUR = 40.3399 Belgian francs).

Source data for federal expenditure for palliative care 2002-2007: Federal Evaluation Cell on Palliative Care. [Evaluation Report Palliative Care 2008] (in Dutch). Brussels: Federal Government Department Public Health, Food Safety and Environment, DG Organisation Health Care Services, Cell Chronic, Elderly and Palliative Care, 2008. Available at: <http://www.health.belgium.be/internet2Prd/groups/public/@public/@dg1/@acutecare/documents/ie2divers/15720532.pdf> (last accessed 13 June 2013).

Government expenditure is made up of funding of PC partnerships (federations and networks), PC at home (multidisciplinary support teams, reimbursement for palliative nursing, GP visits and physical therapy at home) and PC in hospitals (PCUs and PSTs) These figures exclude expenses for PC in day care centres and care homes, which are not available.

Data are inflation adjusted, using the World Economic Outlook (WEO) EconStats data, IMF: <http://www.econstats.com/weo/V016.htm>. (last accessed 13 June 2013).

Data for government expenditure in 2000 are lacking. In 1998 there was no government funding for PC, nor a reimbursement system for health care costs pertaining to PC.

The atlas is based on a survey of national experts and palliative care organisations carried out in 2005 by the EAPC Task Force on Palliative Care Development (Centeno et al., 2007a & b). As in the 2011 EAPC report to the UK Commission on Assisted Dying (Chambaere et al., 2011), we compared the available indicators of the state of development of

palliative care in four large Western European countries where physician-assisted dying is illegal (UK, France, Germany and Spain) with the Netherlands and Belgium. The five available structural indicators, which reflect the supply of services offered by professional palliative care to the public, are the per capita numbers of inpatient palliative care units

and hospices, palliative care beds, support teams in hospitals, home-care palliative care services, and full-time palliative care physicians. The two available professional process indicators are the per capita rate of participation from each country in EAPC conferences as retrieved from EAPC records (EAPC congresses) and the per capita number of PubMed publications per year, retrieved with the search string (“palliative care” OR “hospice care”). In a secondary analysis, for additional clarity, to better inform the debate on the putative inhibition of the development of palliative care by legally regulated physician-assisted dying, we ranked the countries involved for each indicator as well as on an index composed of all rankings.

3. Results

3.1. The Belgian budget for palliative care before and since legal physician-assisted dying

When in 2002 Belgium legally regulated physician-assisted dying, the passing of the law was preceded by a doubling of the federal budget for palliative care (Figure 1).

Support for this boost was unanimous because the merits of palliative care were undisputed and physician-assisted dying, for which legal regulation was then in preparation, was widely

considered unethical if requested and carried out for lack of available professional palliative care. Concomitantly with the law on euthanasia, a law was enacted to ensure universal access to professional multidisciplinary palliative care (Bernheim et al. 2008). This law made palliative care a citizen’s right, anticipating the Prague charter that was recently proposed by the European Association for Palliative care (EAPC) (Radbruch, de Lima, Lohmann, Gwyther, & Payne, 2013). The total Belgian federal expenditure for palliative care, including the national health-insurance expenditure, has grown consistently by an annual average of almost 10 % since the regulation of physician-assisted dying (Figure 1). This far exceeds the governmental norm for growth of health-care expenditure, which was 4.5% over inflation as of 2003, but since 2013 stands at 2% (Gerken&Merkur, 2010). Accordingly, Belgian palliative care has expanded considerably (Federal Evaluation Cell on Palliative Care, 2008). Only 10 % of Belgian physicians think that the physician-assisted dying legislation was detrimental to the development of palliative care (Smets, Cohen, Bilsen, Van Wesemael, Rurup, & Deliens, 2011).

3.2. How does the level of development of palliative care in Belgium and the Netherlands compare with other European countries?

Table 1. Rankings (#) and scores (between brackets) of specific structural palliative care resources and scientific process indicators, per million inhabitants

| | The Netherlands | Belgium (Flanders) | UK | Spain | France | Germany |
|---|-----------------|--------------------|-----------|-----------|-----------|-----------|
| Structural indicators^a | | | | | | |
| 1) Inpatient units (PCUs and hospices) | #1 (5 3) | #2 (4 7) | #3 (3 7) | #5 (2 2) | #6 (1 3) | #4 (3 0) |
| 2) Palliative care beds | #2 (43 9) | #3 (34 8) | #1 (53 1) | #4 (25 3) | #6 (26 6) | #5 (24 6) |
| 3) Palliative support teams in hospitals | #4 (3 1) | #1 (12 4) | #2 (5 1) | #5 (0 6) | #3 (5 1) | #6 (0 7) |
| 4) Home care services | NA | #3 (2 4) | #1 (5 9) | #2 (3 2) | #4 (1 4) | #5 (0 4) |
| 5) Palliative care physicians (full time) | #5 (0 6) | #4 (2 3) | #2 (7 4) | #1 (11 3) | #3 (6 0) | NA |
| Mean rank for structural indicators | 3 0 | 2 6 | 1 8 | 3 :4 | 4 4 | 5 0 |
| Overall ranking for structural indicators | 3 | 2 | 1 | 4 | 5 | 6 |
| Scientific and professional process indicators | | | | | | |
| 6) PubMed publications on palliative care 1991 – 2011 ^b | #1 (55 1) | #2 (45 0) | #3 (39 8) | #6 (8 8) | #5 (13 7) | #4 (18 3) |
| 7) Average proportionate participation in EAPC conferences ^c | #2 (0 26) | #1 (0 62) | #3 (0 22) | #4 (0 12) | #5 (0 19) | #6 (0 07) |
| Mean rank for scientific and professional process indicators | 1 5 | 1 5 | 3 | 5 | 5 | 5 |
| Overall ranking for scientific and professional process indicators | 1 | 1 | 2 | 3 | 3 | 3 |
| Overall level of palliative care | | | | | | |
| Mean rank for all indicators | 2 50 | 2 29 | 2 14 | 3 86 | 4 71 | 5 00 |
| Overall ranking | 3 | 2 | 1 | 4 | 5 | 6 |

^asource: EAPC Atlas of Palliative Care 2005 (Centeno et al., 2007)

^bsource: Briefing paper from the EAPC (Chambaere et al., 2011b)

^cMean % participants per million inhabitants in the 12 research and general EAPC conferences between 2000 and 2011 (successively in Berlin, Palermo, Lyon, The Hague, Stresa, Aachen, Venice, Budapest, Trondheim, Vienna, Glasgow and Lisbon) according to the EAPC records (EAPC congresses)

NA=not available.

The per capita values of the indicators and the rankings of the countries are shown in Table 1. The UK, where palliative care has the longest history, leads in terms of structural indicators, followed by Belgium and the Netherlands. If also the scientific and professional process indicators are taken into account, the two countries with legally regulated physician-assisted dying are found close to on a par with the UK, while a second cluster with a lesser overall level of palliative

care development according to the available indicators comprises Spain, France and Germany.

4. Discussion

Strengths and imitations of the study

This study situates the issue of the development of palliative care among other controversies surrounding legally regulated

physician-assisted dying in the Benelux countries. That our study is the first to rank European countries for level of supply of palliative care services, is a strength. Another strength is also considering the expenditure for palliative care, an important indicator, not only of structural availability of services to the public, but also of their output.

Our analysis has some limitations. For lack of criteria to do otherwise, we gave equal weights to all seven indicators though we recognise that, the organisation of palliative care being different between countries (Centeno et al., 2007a & b), some indicators may be more important in one country than in another. Also, some relevant variables of output are at present available only for Belgium, including palliative care expenditure and the fraction of deaths preceded by professional multidisciplinary palliative care (41% of all non-sudden deaths in 2007 as found by Van den Block et al., 2008). More robust conclusions will be possible when in the future such important indicators become available everywhere and also patient outcomes are taken into account. Also, importantly, for lack of measures of quality of care, we have dealt only with quantitative indicators.

The question whether the culture of competent and compassionate care has been affected in the Benelux countries is more difficult to answer with only quantitative data, which moreover lack patient outcome measures. However, clues that if anything it has improved can be inferred from statements by respected spokespersons for palliative care in Belgium. Palliative care workers who decline physician-assisted dying pledge to work hard at preventing such requests (Gamester & Van den Eynden, 2009) and those who have endorsed physician-assisted dying state to practice it in the philosophy of ‘integral palliative care’, i.e. in the continuity of conventional palliative care, and with the same compassion (Bernheim et al. 2008; Bernheim & Mullie, 2010).

5. Conclusions

This analysis, showing that in 2005 the physician-assisted dying-permissive countries were not lagging behind the non-permissive is in line with the EAPC report to the UK Commission on Assisted Dying (Chambaere et al., 2011) and earlier observations in Belgium (Bernheim et al., 2008), the Netherlands (Gordijn & Janssens, 2004), and the USA (Lindsay, 2009). All suggested that legal regulation of assisted dying can be complementary with palliative care. Also in the Netherlands there is evidence that the legalisation of physician-assisted dying made the need for optimal palliative care more compelling, and boosted its development to its later high level (Janssens & ten Have, 2001; Gordijn & Janssens, 2004). However, whereas in Belgium the development of palliative care preceded and arguably enabled legal physician-assisted dying (Bernheim et al., 2008), the sequence and relationship appears to be inverted in the Netherlands: palliative care took off ‘with a vengeance’ after the 2002 law. All the evidence suggests that also in the physician-assisted

dying-permissive countries the mainstream palliative care tenet of prevention of physician-assisted dying (Saunders, 1976) was an incentive to strengthen palliative care (Gordijn & Janssens, 2000; Bernheim et al., 2008).

In sum, the here reviewed and generated evidence confirms that palliative care and legally regulated physician-assisted dying can coexist and be synergistic. The evidence from Belgium and the Netherlands during the first several years after the implementation of legally regulated physician-assisted dying does not verify the concern that the further development of palliative care would be stunted. However, some effects of legal physician-assisted dying on palliative care development may come to light only in the long run or in the form of phenomena that are not picked up by the currently available indicators. Therefore, there should be continued monitoring of both permissive and non-permissive countries, preferably also including patient outcomes.

6. Keypoints

- Both fundamental and pragmatic arguments are put forth against legally regulated physician-assisted dying, as since 2002 in Belgium and the Netherlands. A prominent pragmatic concern is the possible stunting of the development of palliative care.
- After the legalisation of physician-assisted dying, Belgium’s expenditure for palliative care increased by an annual 10% and in 2005 the state of development of palliative care in the Netherlands and Belgium was close to on a par with the UK and ahead of the other non-permissive countries Spain, France and Germany.
- Well-developed palliative care may be a pre-requisite of legal regulation of physician-assisted dying, but may also be a consequence.
- Because effects of legal physician-assisted dying on palliative care development may manifest only later or in other ways, evolutions in both permissive and non-permissive countries should be further monitored.

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