Written evidence submitted by Professor Jan Bernheim's (ADY0334)

TARGET TOPIC:

2. What can be learnt from the evidence in countries where assisted dying/assisted suicide is legal?

CREDENTIALS.

I am a retired oncologist and an emeritus professor of medicine and medical ethics at the Vrije Universiteit Brussel (Belgium). In the late 1970s, I was with British expats in Brussels a co-founder of probably the first palliative care organisation outside the UK. As of the 1980s, I have proposed and advocated what has been called the Belgian Model of End-of-Life Care, in which palliative care has embedded medical aid in dying (MAID);° thus ensuring continuity of care also for patients requesting euthanasia.° With an 80% multi-partisan majority, this model was endorsed in 2002 by the Belgian Parliament and as of 2003 by the Flemish and later Brussels and Walloon palliative care organisations. Another distinctive feature of the Belgian model is that end-of life services are integral part of national health coverage and, particularly, that their funding is largely demand rather than supply driven.

The philosophical underpinning of this model is to combine two elsewhere often competing ethical paradigms: care ethics and the ethics of autonomy.

I was among the founders of the End-of-Life Care Alliance Research Group of Brussels and Ghent universities, one of the largest research groups in this field: https://endoflifecare.be/.

I was a witness in Canadian Supreme Court, which found the evidence from Belgium 'persuasive'

I have often lectured on these themes in the UK, Canada, Australia and New Zealand. One lecture , at the invitation of the late Lord Joffe, was at a symposium in the House of Lords.

My credentials are detailed in the article Valerie Møller **Jan Bernheim: a Pioneer/Prophet in Getting Serious Answers to the Serious Question 'How are you?'***Applied Research in Quality of Life* **volume 16**, pages911–915 (2021).

Should there be queries on the material submitted below, I'd be happy to respond to them. There are at least two opportunities for this:

- Also I have on behalf of several Belgian experts and stakeholders, including my colleagues of the End-of-Life Care Alliance Research Group of Brussels and Ghent universities invited the Committee to come and visit us in Bruges and/or Brussels for a closer examination of the Belgian model of end-of-life care.

SUBMITTED RELEVANT PUBLICATIONS WITH ABSTRACTS

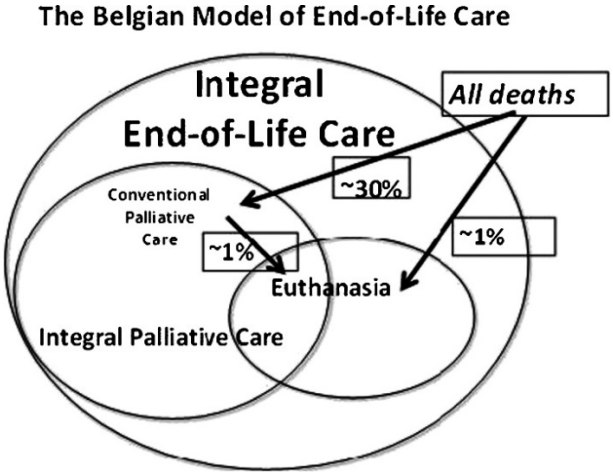
- Bernheim Jl, Deschepper R, Distelmans W, Mullie A, Bilsen J, Deliens L. Development of palliative care and legalisation of euthanasia: antagonism or synergy? *Brit. Med. J.* 336: 864-867, 2008.

  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.

- Jan L Bernheim, Wim Distelmans, Arsène Mullie, Michael Ashby. Questions and answers on the Belgian model of integral end-of-life care: heresy, experiment, prototype. 'Eu-euthanasia': the close historical, and evidently synergistic, relationship between palliative care and euthanasia in Belgium: an interview with a doctor involved in the early development of both and two of his successors.
  J Bioeth Inquiry 11(4): 507-529, 2014. Free download: DOI 10.1007/s11673-014-9554-z IF 2012: 0.594

  Abstract

  This article analyses domestic and foreign reactions to a 2008 report in the British Medical Journal on the complementary and, as argued, synergistic relationship between palliative care and euthanasia in Belgium. The earliest initiators of palliative care in Belgium in the late 1970s held the view that access to proper palliative care was a precondition for euthanasia to be acceptable and that euthanasia and palliative care could, and should, develop together. Advocates of euthanasia including author Jan Bernheim, independent from but together with British expatriates, were among the founders of what was probably the first palliative care service in Europe outside of the United Kingdom. In what has become known as the Belgian model of integral end-of-life care, euthanasia is an available option, also at the end of a palliative care pathway. This approach became the majority view among the wider Belgian public, palliative care workers, other health professionals, and legislators. The legal regulation of euthanasia in 2002 was preceded and followed by a considerable expansion of palliative care services. It is argued that this synergistic development was made possible by public confidence in the health care system and widespread progressive social attitudes that gave rise to a high level of community support for both palliative care and euthanasia. The Belgian model of so-called integral end-of-life care is continuing to evolve, with constant scrutiny of practice and improvements to procedures. It still exhibits several imperfections, for which some solutions are being developed. This article analyses this model by way of answers to a series of questions posed by Journal of Bioethical Inquiry consulting editor Michael Ashby to the Belgian authors.



- Bernheim Jl, Raus K. Euthanasia embedded in palliative care. Responses to essentialistic criticisms of the Belgian model of integral end-of-life care. *J Med Ethics*. 2017 Aug;43(8):489-494.

Abstract

The Belgian model of 'integral' end-of-life care consists of universal access to palliative care (PC) and legally regulated euthanasia. As a first worldwide, the Flemish PC organisation has embedded euthanasia in its practice. However, some critics have declared the Belgian-model concepts of 'integral PC' and 'palliative futility' to fundamentally contradict the essence of PC. This article analyses the various essentialistic arguments for the incompatibility of euthanasia and PC. The empirical evidence from the euthanasia-permissive Benelux countries shows that since legalisation, carefulness (of decision making) at the end of life has improved and there have been no significant adverse 'slippery slope' effects. It is problematic that some critics disregard the empirical evidence as epistemologically irrelevant in a normative ethical debate. Next, rejecting euthanasia because its prevention was a founding principle of PC ignores historical developments. Further, critics' ethical positions depart from the PC tenet of patient centeredness by prioritising caregivers' values over patients' values. Also, many critics' canonical adherence to the WHO definition of PC, which has *intention* as the ethical criterion is objectionable. A rejection of the Belgian model on doctrinal grounds also has nefarious practical consequences such as the marginalisation of PC in euthanasia-permissive countries, the continuation of clandestine practices and problematic palliative sedation until death. In conclusion, major flaws of essentialistic arguments against the Belgian model include the disregard of empirical evidence, appeals to canonical and questionable definitions, prioritisation of caregiver perspectives over those of patients and rejection of a plurality of respectable views on decision making at the end of life.

- Chambaere K, Bernheim Jl, Downar J, Deliens L. Characteristics of Belgian “life-ending acts without explicit patient request”: a large-scale death-certificate survey revisited. *Canadian Medical Association Journal Open* 2014 Oct 1;2(4):E262-7

Abstract

Background: "Life-ending acts without explicit patient request," as identified in robust I nternational studies, are central in current debates on physician-assisted dying. Despite their contentiousness, little attention has been paid to their actual characteristics and to what extent they truly represent nonvoluntary termination of life.

Methods: We analyzed the 66 cases of life-ending acts without explicit patient request identified in a large-scale survey of physicians certifying a representative sample of deaths (n = 6927) in Flanders, Belgium, in 2007. The characteristics we studied included physicians' labelling of the act, treatment course and doses used, and patient involvement in the decision.

Results: In most cases (87.9%), physicians labelled their acts in terms of symptom treatment rather than in terms of ending life. By comparing drug combinations and doses of opioids used, we found that the life-ending acts were similar to intensified pain and symptom treatment and were distinct from euthanasia. In 45 cases, there was at least 1 characteristic inconsistent with the common understanding of the practice: either patients had previously expressed a wish for ending life (16/66, 24.4%), physicians reported that the administered doses had not been higher than necessary to relieve suffering (22/66, 33.3%), or both (7/66, 10.6%).

Interpretation: Most of the cases we studied did not fit the label of "nonvoluntary life-ending" for at least 1 of the following reasons: the drugs were administered with a focus on symptom control; a hastened death was highly unlikely; or the act was taken in a ccordance with the patient's previously expressed wishes. Thus, we recommend a more nuanced view of life-ending acts without explicit patient request in the debate on physician-assisted dying.

- Chambaere K, Bernheim Jl. Does legal physician-assisted dying impede the development of palliative care? The Belgian and Benelux experience.
J Med Ethics 41(8):657-60, 2015

Abstract

Background: In 2002, physician-assisted dying was legally regulated in the Netherlands and Belgium, followed in 2009 by Luxembourg. An internationally frequently expressed concern is that such legislation could stunt the development of palliative care (PC) and erode its culture. To study this, we describe changes in PC development 2005-2012 in the permissive Benelux countries and compare them with non-permissive countries.

Methods: Focusing on the seven European countries with the highest development of PC, which include the three euthanasia-permissive and four non-permissive countries, we compared the structural service indicators for 2005 and 2012 from successive editions of the European Atlas of

Palliative Care. As an indicator for output delivery of services to patients, we collected the amounts of governmental funding of PC 2002-2011 in Belgium, the only country where we could find these data.

Results: The rate of increase in the number of structural PC provisions among the compared countries was the highest in the Netherlands and Luxembourg, while Belgium stayed on a par with the UK, the benchmark country. Belgian government expenditure for PC doubled between 2002 and 2011. Basic PC expanded much more than endowment-restricted specialised PC.

Conclusions: The hypothesis that legal regulation of physician-assisted dying slows development of PC is not supported by the Benelux experience. On the contrary, regulation appears to have promoted the expansion of PC. Continued monitoring of both permissive and non-permissive countries, preferably also including indicators of quantity and quality of delivered care, is needed to evaluate longer-term effects.

Should there be queries on this material, I'd be very happy to responds to them.

Jan 2023