Vrije Universiteit Brussel & Ghent University
end-of-life care research group

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Empirical Studies:

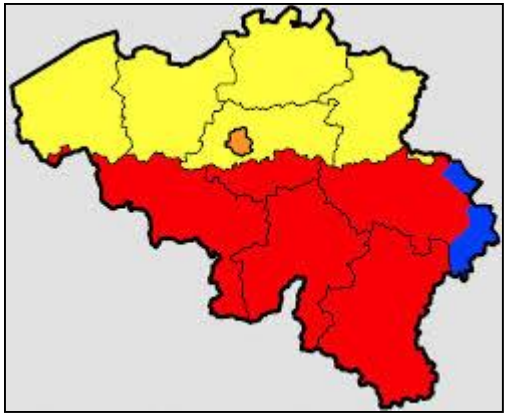
What do we know 15 years after implementation of the Law on Euthanasia in Belgium?

Luc Deliens

Director EOLC Research Group
Universiteit Gent & Vrije Universiteit Brussel

Professor of Palliative Care Research in Belgium

Euthanasia legalized in September 2002 in BE



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Definition of euthanasia

Belgian euthanasia law

- the administration of drugs with the explicit intention to end the life of a person at his or her explicit request
- euthanasia can only be performed by a physician

Legal due care criteria for euthanasia in Belgium

- patient:
  - is competent
  - has to be well informed about his/her
    - situation (diagnoses and prognoses)
    - about all possible therapeutic options, incl. on palliative care
  - the request for euthanasia must be personal, repeated, consistent and not being caused by external pressure
  - the request must also be written

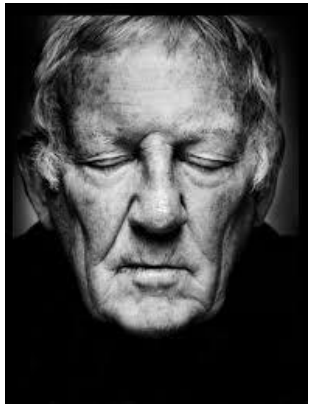
Legal due care criteria for euthanasia in Belgium

- physician knows:
  - whether the request for euthanasia is both voluntary and well-considered
  - whether the medical situation of the patient is without prospect of improvement
  - whether the patient's suffering is unbearable

Legal due care criteria for euthanasia in Belgium

- Some procedural due care criteria:
  - the attending physician needs to consult another "independent physician"
    - two in case the patient is not terminally ill
  - the physician has to report the case to the Federal Control and Evaluation Committee
    - 16 members: physicians, lawyers, EOL specialists

Exceptional cases headlining the news abroad:



Early dementia (Hugo Claus)

Severe chronic depression

Deaf & blind twins (Verbessem brothers)

Failed sex change operations (Nathan Verhelst)

Psychiatric disorders (Frank Van Den Bleeken)

Old age: tired of life (Simona De Moor)

2002 implementation of the Euthanasia Law

What is mostly NOT known abroad on the euthanasia practices in Belgium ?

- Two yearly Reports by the **Federal Control and Evaluation Committee**

- Results of **20 years of research** on euthanasia and ELDs
  - Several PhD theses on euthanasia
  - > 100 peer review papers in international medical journals

What can be critizised in Belgium?

- **Federal Control and Evaluation Committee** have very limited information on the quality of these practices

- The implementation process has been **poorly monitored** and evaluated by the authorities (parliament & government)

- A large **hidden grey zone** related to euthanasia stays completely out of any societal control and evaluation (eg palliative sedation, NTDs, etc)

Hidden related zones in medical practice?

- Euthanasia cases that are not reported to the Committee
- The involvement of palliative care prior to euthanasia is not systematically reported
- Euthanasia request that have not been granted
- The relationship between euthanasia and other ELDs
- Cases of terminal sedation are not reported
- Cases of pain- and symptom treatment with a life shortening intend are not reported
- All cases of life termination without explicit request by the patients are not reported

Repeated ELD surveys by the EOLC research team

Large scale samples of death certificates

1998 – 2007 – 2013

8-12% sample fractions of all deaths in the studied years

Mail survey to the attesting physicians

Short 4 pg validated questionnaire

Anonimity is garanteed for both patient and physician

1998: 49% response rate, 1925 cases analyzed

2007: 58% response rate, 3625 cases analyzed

2013: 61% response rate, 3751 cases analyzed

The NEW ENGLAND JOURNAL of MEDICINE

Recent Trends in Euthanasia and Other End-of-Life Practices in Belgium

TO THE EDITOR: In Belgium, where euthanasia was legalized in 2002, large-scale repeat surveys have monitored the evolution of medical life practices since 1998, with subseque veys conducted in 2001 and 2007[1,2] and th in 2013.

As was done in previous surveys,[2] v questionnaires to 6188 physicians ce death certificates from the first half of Flanders, the Dutch-speaking half of B with approximately 6 million inhabitar 58,000 deaths annually (see the Supple Appendix, available with the full text of ter at NEJM.org). The response rate was The response sample was weighted to b sentative of all the deaths that occurred between 2007 and 2013, from 1.9 to 4.6% of deaths. The overall increase relates to increases

JAMA Internal Medicine
Formerly Archives of Internal Medicine

Letters

RESEARCH LETTER

Comparison of the Expression and Granting of Requests for Euthanasia in Belgium in 2007 vs 2013

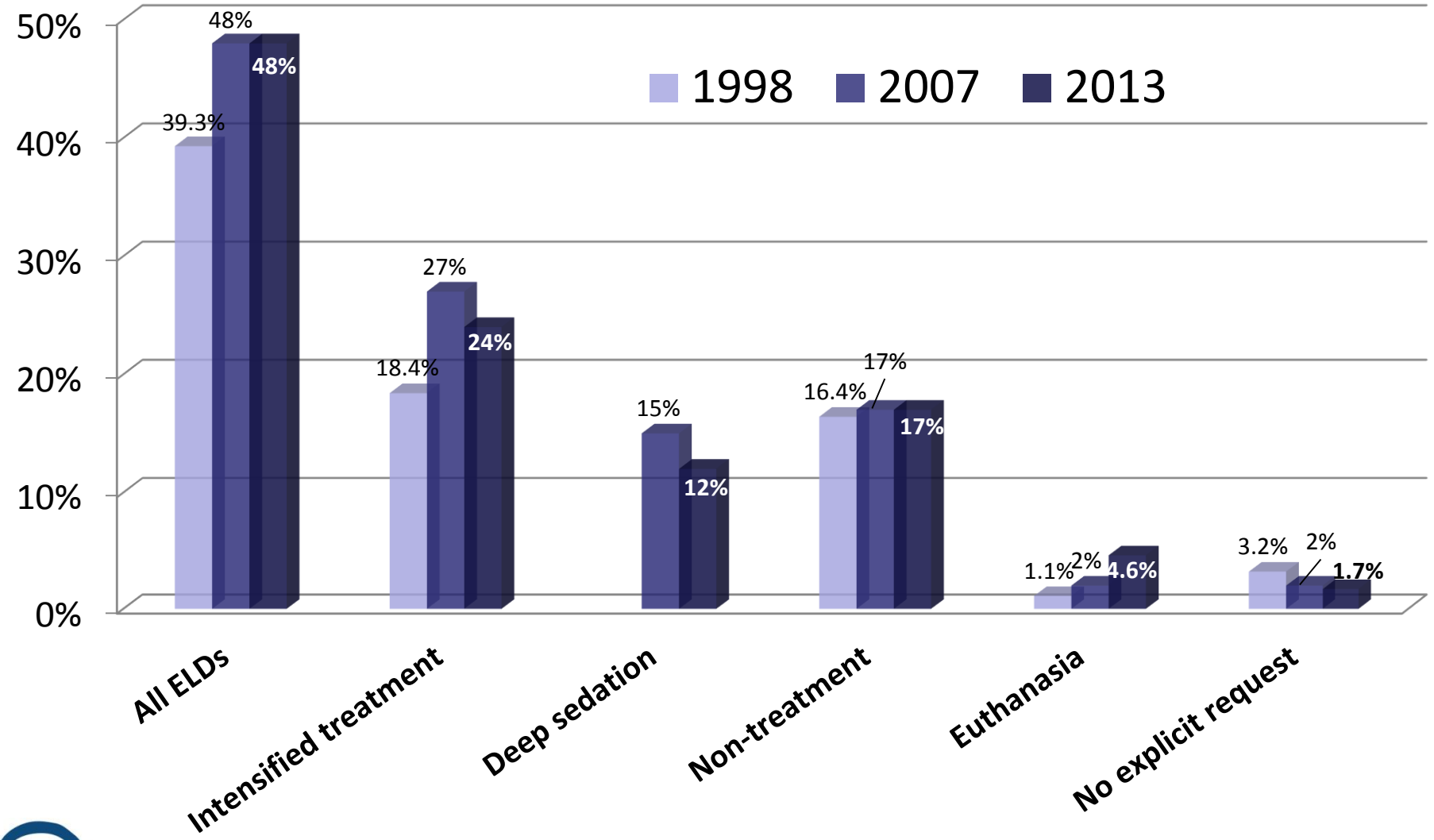
Belgium legalized euthanasia in 2002.[1] Between 2007 and 2013, the prevalence of euthanasia in Flanders, the Dutch-speaking part of Belgium, increased from 1.9% to 4.6% of all deaths.[2] Here we describe the shifts (overall and in specific groups of patients) in the expression and granting of euthanasia requests during this period and the reasons that physicians granted or denied these requests.

Invited Commentary
Related article

Methods | Approval was obtained from the Ethical Review Board of the University Hospital of the Vrije Universiteit Brussel, the Belgian Privacy Commission, and the Belgian National Disciplinary Board of Physicians. Patients were deceased, so no consent could be obtained. Physicians' participation was regarded as implicit consent.

We conducted a nationwide postal questionnaire survey in 2013 that was identical to a survey conducted in 2007 of physicians who certified a random sample of 6871 deaths that occurred from January 1 through June 30, 2013, in Flanders; details of the study design have been published elsewhere.[2] The survey was conducted from March 1 through December 31, 2013. Data analysis was conducted from March 1 through March 31, 2015. The questionnaire asked whether

Evolution ELDs 1998-2013



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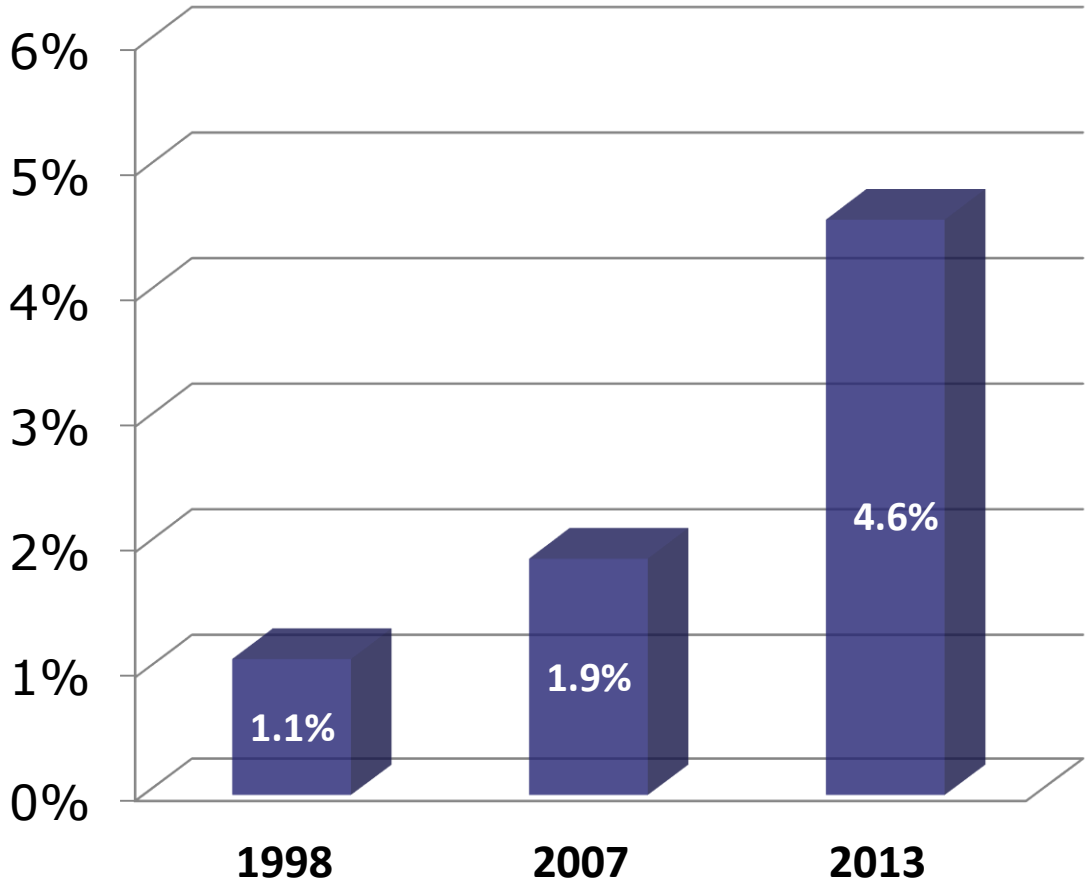
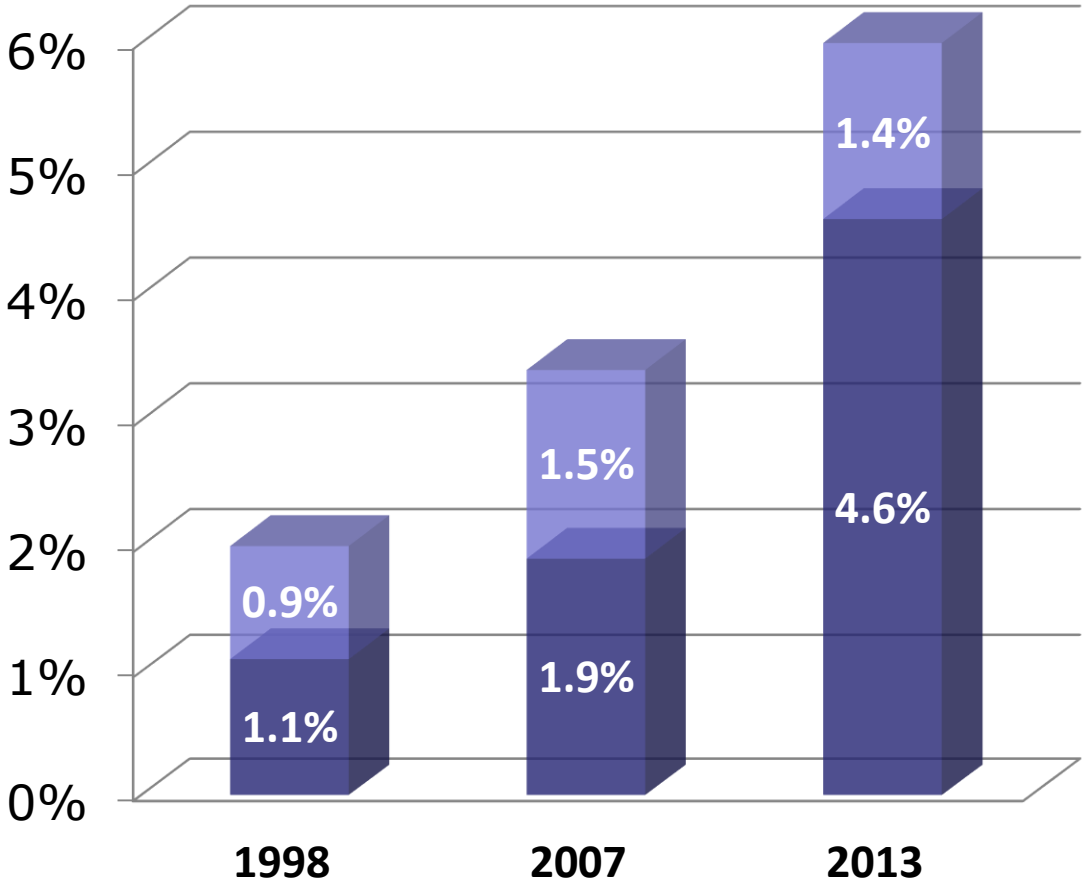
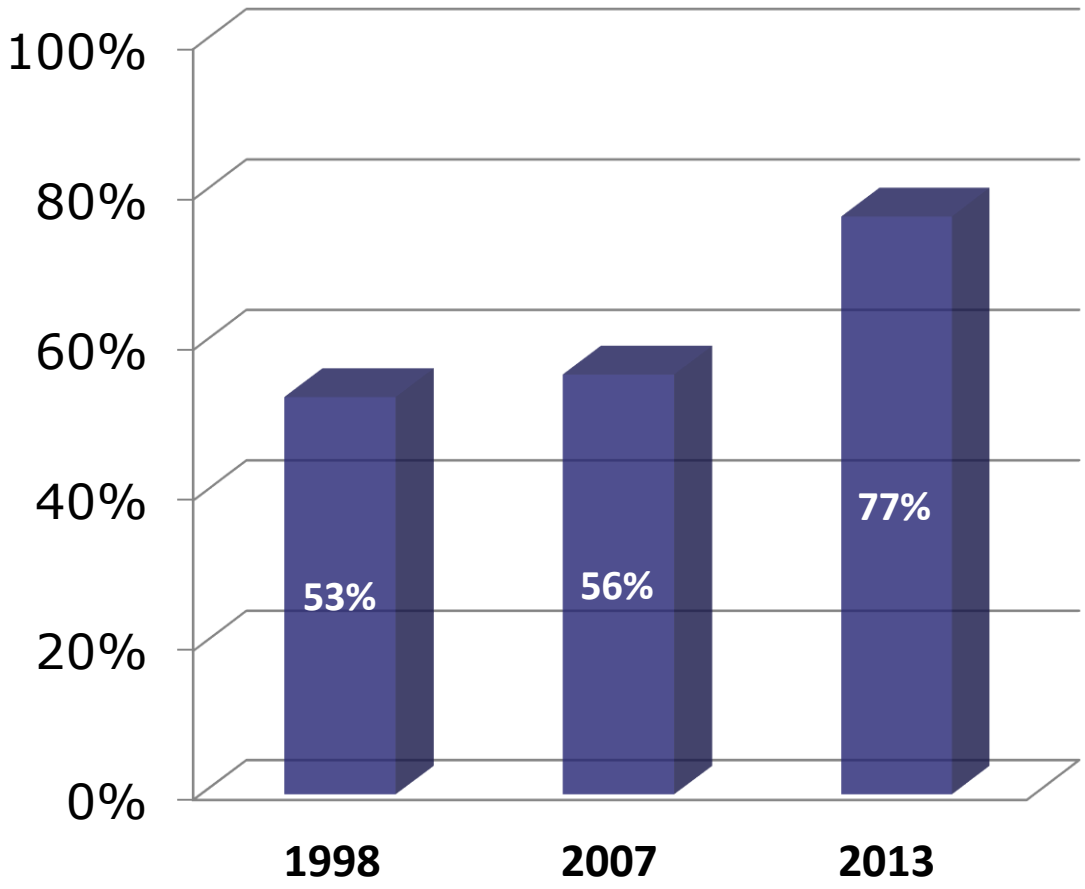
Prevalence of euthanasia



Number of euthanasia requests



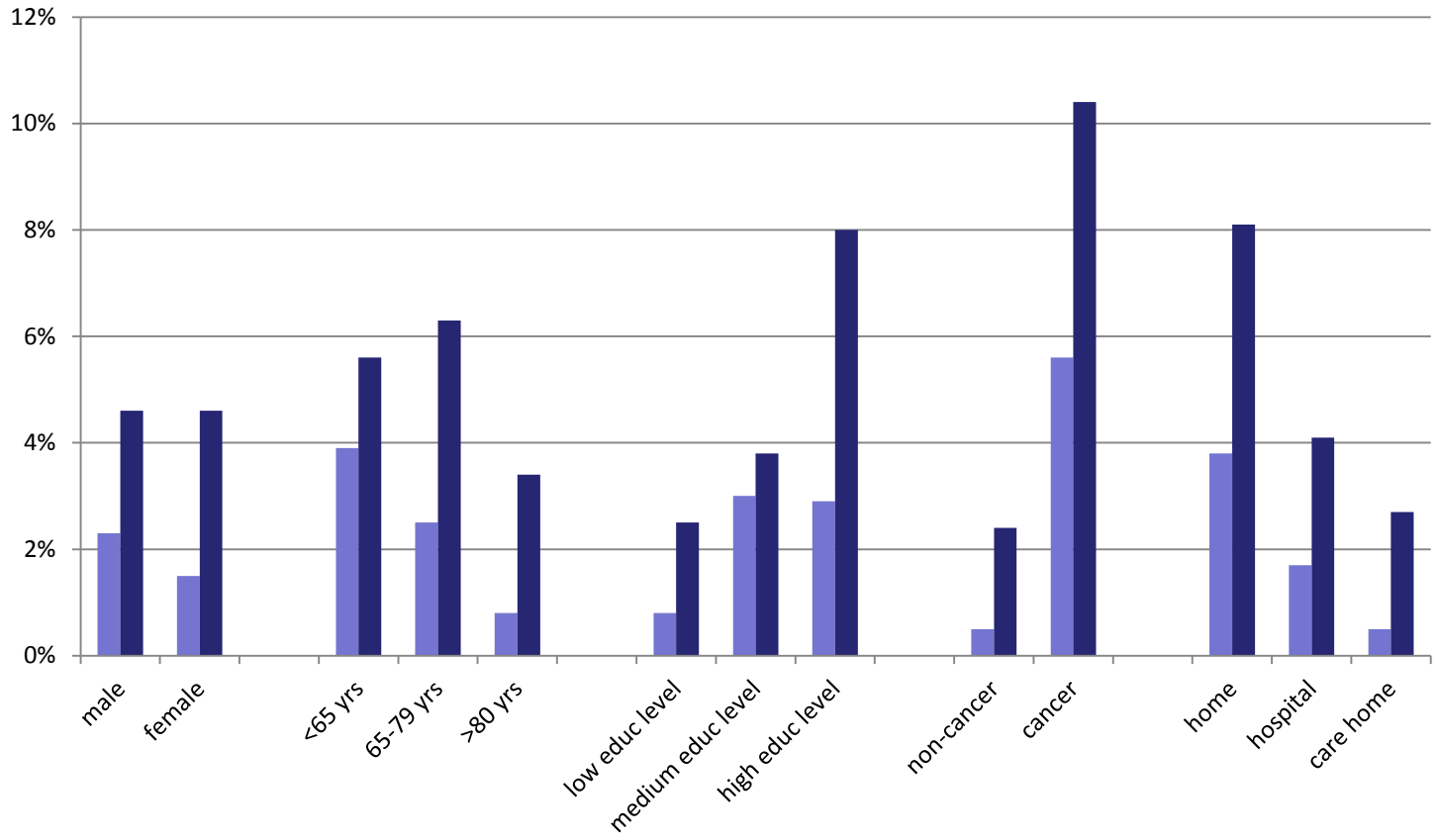
Proportion of requests granted



Increase euthanasia prevalence: which patients?

2007-2013: increase in most patient groups & settings

Highest prevalence at home in younger cancer patients



How to explain the increase in euthanasia cases?

1. *increase of the number of requests by patients*
2. *growing willingness of physicians to grant these*

Why is there an increase in euthanasia requests?

- ➔ high visibility and positive perception regarding euthanasia in the general media
- ➔ many people have direct or indirect positive personal experiences with euthanasia in their family/friends (cfr perception of a “good death”)
- ➔ our society became more open towards talking about death and dying (palliative care, ACP,…) (cfr less of a taboo than 15y ago)

How to explain the increase in euthanasia cases?

1. *increase of the number of requests in patients*
2. *growing willingness of physicians to grant it*

Why are physicians more willing to grant a request?

- ➔ more self efficacy in the procedure and handling of a request
- ➔ more convidence in a positive evaluation by the Review C
- ➔ positive experiences with supporting patients & families in cases of euthanasia
- ➔ less barriers in the health care system, e.g. a nursing home that does not allow euthanasia

Is there an indication of a “slippery slope”?

<u>No empirical evidence for a slippery slope</u>

- More life ending without patient’s request?

  → NO, decrease since the implementation of the law

- Higher risk for vulnerable groups?

  → NO, disproportional low incidence of euthanasia

Conclusions concerning euthanasia developments in BE 2001 - 2013

- legal changes concerning euthanasia in Belgium since 2002 had a considerable impact on the incidence of ELDs in general
- performance of euthanasia since the euthanasia law in Belgium is increased substantially (1% to 4% of all deaths)
- however, developments over time do not show any indication to support the "slippery slope" hypothesis or the hypothesis that euthanasia is applied in "vulnerable" groups

Conclusions concerning societal control

- in order to remain societal control over these "last resort" end of life practices, **monitoring** is needed of all ELDs
- External review of euthanasia in Belgium helps to improve the quality of the EOL practices
- However, the review is based on too limited data

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