Euthanasia and Physician-assisted Suicide -
a White Paper from the European Association for Palliative care…
…and lessons from the Belgian experiment

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Programme

- Part 1: The EAPC White Paper on euthanasia and PAS: content and interpretation…
- … as a challenge for the end of life care in Belgium : Part 2

  => Debate

Part One:
the Stance of the EAPC

2015 :

Euthanasia and physician-assisted Suicide.

A white paper from the European Association for Palliative care

Authors

- **Lukas Radbruch, Carlo Leget**, Patrick Bahr, Christof Müller-Busch, John Ellershaw, Franco de Conno, **Paul Vanden Berghe …**
- … **on behalf of the board members of the EAPC** (endorsed on April 11th 2015)
- Published in Palliative Medicine November 2015 – not yet in paper

2003 - 2015

Revision of

"Euthanasia and physician-assisted suicide: a view from an EAPC Ethics Task Force", Materstvedt L J, Clark D, Ellershaw J, Forde R, Boeck Gravgaard A-M, Müller-Busch H Ch, Porta i Sales J, Rapin C-H in

Palliative Medicine 2003; 17: 97-101

“Looking for the differences” (I)

- Much more elaborated: 4 -> 13 pages
- Different authorship: by method an EAPC text (Delphi), rather than a text by a group of authors *(Ethics Task Force),* broader supported - be it less consensual
- Taking into account new evolutions (societal, legal, scientific, …) since 2003

“Looking for the differences” (II)

- Goes more into palliative sedation
- Recognizes a different practice in some countries (the Netherlands and Belgium)
- But it holds to the structure and the stance of the 2003 White Paper

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- Background
- Historical trends and current situation
- Aims
- Methods
- Concepts and definitions: (1-6)

Table of content (bis)

- Palliative care values and philosophy (7)
- Key issues on the patient level (8-14)
- Key issues on the organizational level (15-21)
- Conclusions

Background

- 1991 – 1994 – 2003 - 2015
  - 2001 – 2002 – 2009 + Switzerland & USA
  - Non-treatment decisions + palliative sedation
  - Discussion, incompatible normative frameworks

  => How to deal with negative outcome/side-effects of unprecedented medical progress?

Aims

- Ethical framework for professionals
- Description of recent evolutions
- To allow for cultural differences
- What is the position of the EAPC:

  clear recommendations
- Description of controversies and foster the debate

Target group - Methods

- Target group: all palliative care professionals and others - legal, political and philosophical experts

- Methods: consensus document starting from litterature - Delphi consultation by experts and board members of national associations in 5 rounds – EAPC Board

Historical trends and current situation

- 1996: Euthanasia (E) & Physician Assisted Suicide (PAS) in Australia: proposal made ineffective in 1997
- PAS: Oregon (1997) - Washington (2008) – Vermont (2013) and California (2015): +/- 0,25% of all deaths
- Switzerland: Assisted suicide, not *physician* assisted : +/- 0,5%

- The Netherlands (2001) & Belgium (2002) & Luxembourg (2009): conditional decriminalisation of euthanasia :
- The Netherlands: 3,4% - Belgium: 1,35 – 4,6% of which 82% in Flanders
- Europe in general

Concepts and definitions: (1-6)

- (1) Palliative care is an approach that improves the quality of life of patients and their families facing the problems associated with life-threatening illness, through the prevention and relief of suffering by means of early identification and impeccable assessment and treatment of pain and other problems, physical, psychosocial and spiritual (WHO)

Concepts and definitions: (2)

- (2) Euthanasia is defined as follows:

  a physician (or other person) intentionally killing a person by the administration of drugs, at that person's voluntary and competent request.

'non- or in-voluntary E' : voluntary only

'passive or active E' : active by definition

Concepts and definitions: (3)

- (3) Assisted suicide is defined as follows:

  a person intentionally helping another person to terminate his or her life, at that person's voluntary and competent request.

Concepts and definitions: (4)

- (4) Physician Assisted Suicide (PAS) is defined as follows:

  a physician intentionally helping a person to terminate his or her life by providing drugs for self-administration, at that person's voluntary and competent request.

Concepts and definitions: (5)

- (5) Non-treatment decisions (NTD) are defined as follows:

  withholding or withdrawing medical treatment from a person either because of medical futility or at that person's voluntary and competent request.

Concepts and definitions: (6)

- (6) Palliative sedation is defined as the monitored use of medications intended to induce a state of decreased or absent awareness (unconsciousness) in order to relieve the burden of otherwise intractable suffering *in a manner that is ethically acceptable to the patient, family and healthcare providers.*

Palliative care values and philosophy

- (7) In palliative care, the intrinsic value of each person as an autonomous and unique social individual is acknowledged and respected. Ideally, the patient preserves his or her self-determination regarding the power of decision on place of care, treatment options and access to specialist palliative care.

Key issues on the patient level (8-14)

- (8) Individual requests for euthanasia and PAS are complex in origin and may include personal, psychological, spiritual, social, cultural, economic and demographic factors.

Key issues on the patient level (9-10)

- (9) Requests for euthanasia and PAS require respect and careful attention, together with open and sensitive communication in the clinical setting.
- (10) Individuals requesting euthanasia or PAS should have access to palliative care expertise.

Key questions on the patient level (12)

- (12) Palliative sedation in those imminently dying must be distinguished from euthanasia:
- Intention: to relieve intolerable suffering vs.

  to end the life of the patient
- Procedure : to use a sedating drug for symptom control vs.

  to administer a lethal drug
- Outcome: the alleviation of distress vs.

  immediate death.

Key questions on the patient level (13)

- (13) Palliative care is provided up until the end of life and is by definition never futile.

Key questions on the patient level (14)

- (14) The provision of euthanasia and PAS should not be included into the practice of palliative care.

Key issues on the organizational level (15-21)

- (15) It is recognized that within Europe several approaches to euthanasia and PAS are emerging, and open and respectful debate surrounding this is to be encouraged.

Key issues on the organizational level (16)

- (16) Studies of attitudes to euthanasia and PAS among professionals, patients and the wider public as well as studies of their experiences of these issues may inform the wider debate.

Key issues on the organizational level (17)

- (17) Fear of loss of autonomy at the end of life can be addressed using advance directives and ACP, contributing to improved communication and thereby enhancing the autonomy of the patient.

Key issues on the organizational level (18)

- (18) If euthanasia or PAS is legalized in any society, there should be special attention to avoid (i) the underdevelopment or devaluation of palliative care and (ii) conflict between legal requirements and the personal and professional values of physicians and other healthcare professionals.

Key issues on the organizational level (19)

- (19) In the case of legalization of euthanasia or PAS, special attention should also be paid to avoid (i) the widening of the clinical criteria to include other groups in society, (ii) pressure on vulnerable persons and (iii) killing to become accepted within society.

Key issues on the organizational level (20)

- (20) The EAPC encourages its members to engage in direct and open dialogue with those who promote the legalization of euthanasia and PAS.

Key issues on the organizational level (21)

- (21) EAPC does respect individual choices for euthanasia and PAS but stresses the importance of refocusing attention onto the responsibility of all societies to provide care for their older, dying and vulnerable citizens. A major component in achieving this is the establishment of palliative care within the mainstream healthcare systems of all European countries supported by appropriate finance, education and research.

Conclusion: Implications for practice, theory or policy

- Individual requests for euthanasia and physician-assisted suicide (PAS) are complex in origin and may include personal, psychological, spiritual, social, cultural, economic and demographic factors. Such requests require respect and careful attention, together with open and sensitive communication in the clinical setting.

Implications II

- The EAPC position paper states that the provision of euthanasia and PAS should not be included into the practice of palliative care.
- Individuals requesting euthanasia or PAS should have access to palliative care expertise. This should be achieved by the establishment of palliative care within mainstream healthcare systems of all European countries supported by appropriate finance, education and research.

Implications III

- Within Europe, several approaches to euthanasia and PAS are emerging, and open and respectful debate surrounding this is to be encouraged.

Part Two: the Belgian experiment

- The BeNeLux: a laboratory for a three-nationwide experiment on euthanasia
- An outline of 13 years Belgian experience, with beneficial and worrisome evolutions …
- … and how this reflects the 21 statements of the White Paper, in one way or another...

A concise history of PC & Eu in Belgium (I)

- Palliative scene in Belgium: well developed before 2002 ⇔ The Netherlands
- Political action starting from progressive circles, against the majority of the medical corps
- The palliative world : divided on the topic of Euthanasia…
- But we engaged in the debate

A concise history (II)

- No genuine and free choice for E if good PC is not guaranteed
- No E without substantial development of PC
- -> « palliative filter » (obligatory palliative consultation): did not pass in 2002
- With good PC, requests for E will disappear…

A concise history (III)

- 2002: three laws: regarding the patients rights, PC and E (# PAS)
- The budget for PC : doubled in 2002, but hardly any important measures ever since…

  +/- 0,4% of Public Health expenditures

Broeckaert B, e.a., *Ethical Perspectives 2002*

Centre Fédéral d'Expertise des soins de santé, *Organisation des soins palliatifs en Belgique,* KCE Reports 115B, 2009

28 May 2002: Law on Euthanasia

- Definition : “the intentional termination of the life of another person, at his request”
- Conditions: substantive: Repeated consistent request, under no external pressure, in writing (+ witnessed written advance directives for the case of irreversible state of out of consciousness) by a competent adult patient. – Medically hopeless condition - Intolerable and irreversible suffering, physical and/or mental - Caused by an irreversible medical condition (accident or disease) - procedure: Patient duly informed of his condition, life-expectancy and alternatives, including palliative care, reaching the conclusion that there is no other reasonable solution – possibility of communication about request with significant others, if wish of patient - Carried out by MD, after consultation of nursing team and a competent and independent colleague’; MD present until death - If patient not expected to die within foreseeable future, 2 independent colleagues must be consulted and a moratorium of 1 month respected - Reported to Federal Euthanasia Control and Evaluation Committee
- No ‘right to E’!

Our experience …

- Not a theoretical – ethical issue (anymore)
- But a practical – ethical one:

FACT: There is A LAW on euthanasia…

HENCE: HOW TO DEAL with this reality given the legal possibility?

What if our patient requests euthanasia?

… your challenge?

- Increasing euthanasia acceptance in Europe

  (Cohen, J., EJPH 2012)
- Growing pressure by the general public to legalise euthanasia, a majority in many European countries
- How to realise/preserve/promote the fundamental values of PC?

In Flanders: A mind shift …

- PC # E, but they can be considered together when caring for one and the same patient, in spite of the WHO definition of PC
- Before the E-request emerges :

  a. “Doctor, I want this to stop”: the fear of E should not impede good PC (e.g. withhold treatment)

  b. Sometimes, responses of PC interventions are poor, E can serve a good death

From a negative motivation…

The lesser evil: “We cannot *not* be involved.”

- Euthanasia – even correctly administrated – *outside* the context of the regular and familiar care team: less than optimal care
- ‘Backwards involvement’: initially hesitating and reluctant, care givers witnessed good euthanasia care and got involved more on the next occasion : “Euthanasia *can* be a genuine good death.”

… to a positive motivation

- Specific indications for E: not the failure of PC, but **A**nxiety, **B**urn out by treatments, desire to be in **C**ontrol and fear of dependency, **D**epression, **E**xistential despair…
- PC in the service of E: added value of a specialised and multidisciplinary team for:

  - complex symptoms exceeding the competence of primary care givers

  - full information on all palliative options and 'no other reasonable solution (cf. Art. 3, § 2, 1° Law on E)

=> **"In the name of continuity of care, we chose not to abandon our patients requesting E"**

A true ethical labour…

Ethics of care: “autonomy in relationship”

1. Deep respect for differences in personal participation & no normative stance or judgement on individuals
2. The patient can understand that a professional or a team does not feel comfortable with a request – Clear and timely communication – Let them stay on board!

A true ethical labour…(II)

3. A euthanasia-act is to be felt as understandable and right.
4. Against trivialisation :

   “Euthanasia should hurt.” (G. Kimsma)

… care beyond the law

The practice of care ‘beyond the law’: ‘careful ànd caring’

- Careful : correct regarding the legal conditions
- Caring: and considerate: much more care than required by the law: multidisciplinary support, communication, bereavement …

⇒ the importance of being involved as PC (<-> NL) – no societal support for assisted suicide in Belgium – *Physician* Assisted : need for a medical ground

FPCF 2011:‘Palliative Care and Euthanasia’:

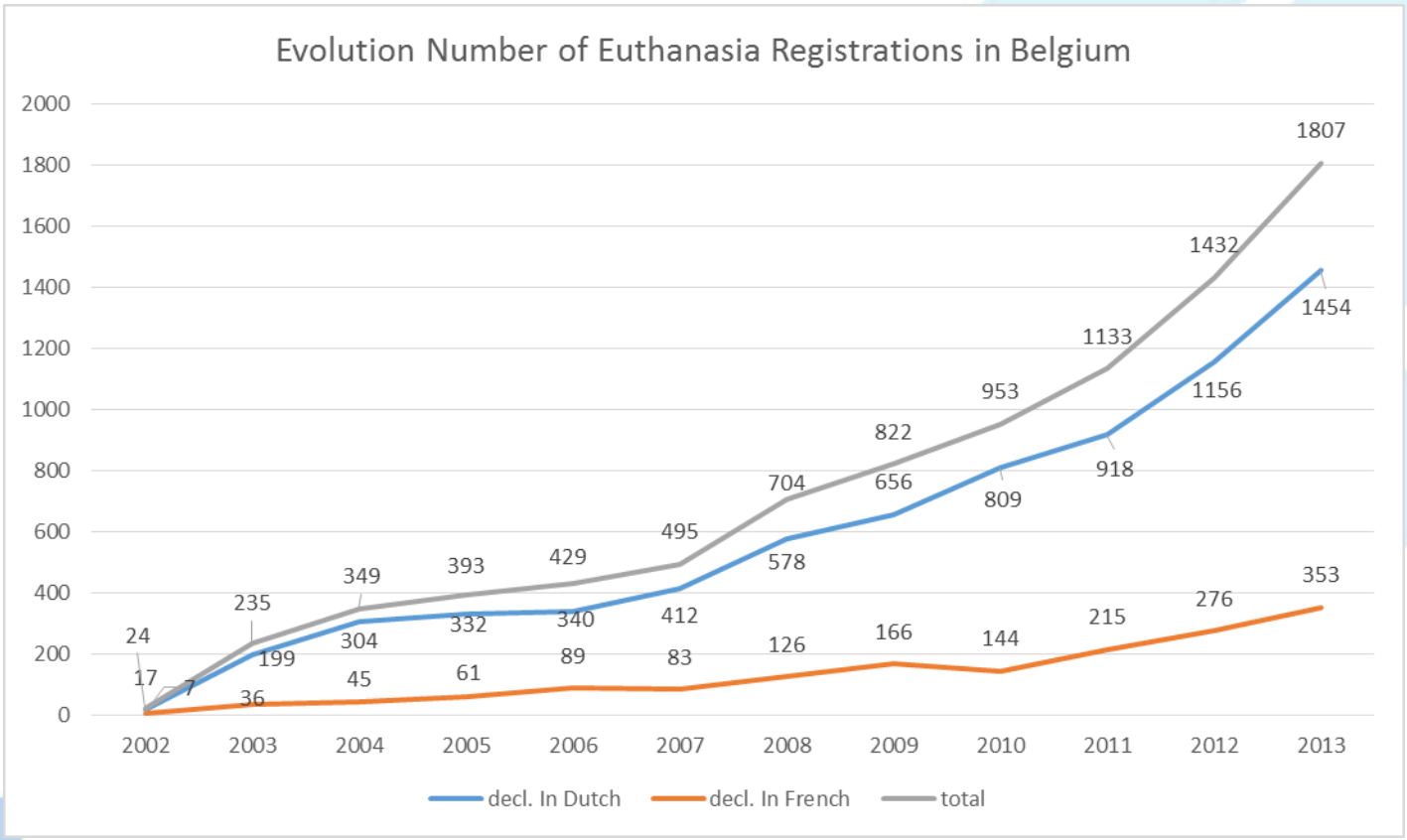
Affirms and recommends its trajectory:

- Palliative care has an open attitude towards euthanasia:
- With their multidisciplinary character, the palliative teams dispose of the highest standards of palliative competencies, including those of communication, and are therefore well equipped for the practice of end-of-life-care, also for the accompaniment of euthanasia: “both in a careful (regarding the legal conditions) and caring way.”

But palliative consultation as an **offer**,

not an **obligation** (WP 13)

6th Report of the Belgian Federal Euthanasia Control and Evaluation Committee (2012-2013)



The white paper and Belgium: a mutual challenge

- Euthanasia by preference accompanied by health and palliative care (WP 9. 10. 13)
- 6/10 requests disappear when taken care of by palliative care, 4/10: desire to be in control, rather than caused by (acute) suffering # failure of PC (WP 8. 11)
- Euthanasia can be a way of genuine ‘good death’, ‘framing’ the whole life and ‘fitting’

Beneficial effects?

- Three laws: catalysts for advance care planning (ACP) (WP 17)
- Regarding knowledge of end-of-life decisions, the decision making process, communication… but still plenty to do!
- Absolute need for a clear conceptual framework (WP 1-6) (palliative sedation # 'slow euthanasia')

Beneficial effects?

- Our patients have shown us the way: If E is strictly speaking not part of PC, they can meet in one and the same patient…
- Dialogue instead of discussion: the work took away the sharp edges and brought wisdom beyond polarisation and ideology
- https://www.youtube.com/watch?v=x3S1KLx61A0
  President FPCF English spoken

Euthanasia embedded in Palliative Care

- Flanders 2012: 50% of non-sudden deaths; accompanied by specialised PC
- E: 4,6% of all deaths - 73,7% of all euthanasias preceded by a PC trajectory (Chambaere &Deliens NEJM 2015)
- Against antagonism PC - E: (#WP 14) Vanden Berghe P, Mullie A, Desmet M, Huysmans G. Assisted dying – the current situation in Flanders: **Euthanasia embedded in palliative care** , EJPC 2013; 20: 266-72. link

Our concerns

- Legalism and proceduralism
- Euthanasia following its own course: tendency to extend the law towards minors (2014), dementia, tired of living … (WP 19 i)
- Instrumentalisation: 'Dying 2.0': social construct vs. 'Slow dying'? (WP 19 ii & iii)
- often very poor care: www.sbs.com.au/dateline or http://www.newyorker.com/magazine/2015/06/22/the-death-treatment
- Defective parliamentary control

Our concerns (II)

- Substantial increase and problematic workload, insufficient budget: PC victim of its success (WP 18 i)
- Cave argument of economics by PC: QOL first (the more that E is much more cost-effective)
- ‘Twin track-policy in the end-of-life care’: E <-> SP : separate E-advocates and End of Life clinics

Our challenges

- Education: knowledge and good practise
- Development of guidelines (Palliative sedation # ‘slow euthanasia’
- Also of the public: ‘medical hopelessness’?
- The problem of prolonged death
- The head start of PC on E is threatened : priority to PC! (WP 21)
- Scientific research – qualitative studies (WP 16)

Be prepared:

- For the discussion, also on societal level:

  PC, E, PAS, relation PC –E …,
- For your patients: what are you going to answer them?
- For your team: considerable impact
- Reinforce PC as much as possible
- If the law changes: get involved!

"What about ethics in all this?"

- Ongoing *dialogue* against incompatibility of viewpoints (WP 15.20)
- Get involved: in the dialogue, in the care for the patients with an euthanasia request, …
- = dirty hands <-> die Schöne Seele
- Freedom of conscience: towards euthanasia, not towards sedation

"What about ethics in all this?"

- The lesser evil + also in the illicit, there is still right and wrong, = ethics
- Care (and ethics) beyond the law
- Attention for new ethical challenges
- Against activism: being present - 'Gelassenheit'/equanimity & acceptation of impotency and of a certain arbitrariness

Thanks for your attention!

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