Involvement of palliative care in euthanasia practice in Flanders, Belgium: a population-based mortality follow-back study

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Paper

Original Article



Involvement of palliative care in euthanasia practice in a context of legalized euthanasia: A population-based mortality follow-back study

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Increasing number of jurisdictions worldwide considering and legalising euthanasia

Commonly stated that euthanasia does not fit well with palliative care (PC) – e.g. the European Association for Palliative Care (EAPC)

Strong opposition:

- Incompatible with PC values ("not hasten death")
- Detrimental to PC as a profession and as a movement
- Argument that adequate PC makes euthanasia redundant

PC clinicians increasingly likely to be confronted with euthanasia requests. How do they respond in a context of legalised euthanasia?

Belgium = interesting case study for relationship PC & euthanasia

Twin laws: euthanasia law + law on palliative care in 2002 Why? Recognition that euthanasia should not be performed for lack of the best possible (palliative) care at the end of life

Law on palliative care

- Structural embedding of palliative care in health care organisation: palliative function in all care settings
- Universal access to palliative care (=patient right)
- Reimbursement through health care insurance system (palliative status, lump sum, palliative leave)

Federal budget for palliative care doubled between 2002-2011 (Chambaere & Bernheim 2016)

Belgium ranks among best countries in Europe – in terms of number of palliative care services per million inhabitants (Chambaere & Bernheim 2016)

Reach (anno 2013): specialist PC involved in EOL care in nearly half of all non-sudden deaths in Flanders (Beernaert et al 2015) BUT only shortly before death (median: 10 days)

Belgian euthanasia law does not include compulsory palliative care consultation (="palliative filter")

However, requirement for physician to inform patient of all available reasonable treatment options, including palliative care.

Patient is not required to try palliative care as it is a patient's right to refuse treatment, including palliative care treatment.

No requirement to report involvement of palliative care professionals on euthanasia report form to Federal Control and Evaluation Committee for Euthanasia

Position Federation for Palliative Care Flanders

2003: "No polarisation, but dialogue and respect"

"Palliative care involvement in euthanasia requests"

2011: "Palliative care can guarantee that euthanasia requests will be dealt with in a careful and caring way"

2013: "Euthanasia embedded in palliative care" (Vanden Berghe et al, 2013)

Model of integral end-of-life care
"Euthanasia at the end of a palliative care pathway"
(Bernheim et al, 2008)

Synergistic development:

- 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

Research questions

- How often are palliative care services involved in the end-oflife care of people who request euthanasia?
- What are the reasons for physicians not to refer a patient requesting euthanasia to a palliative care service?
- Does the granting rate of euthanasia requests differ according to the involvement of palliative care services in end-of-life care?
- What is the role of palliative care professionals in the decisionmaking process and performance of euthanasia?

Method

Mortality follow-back survey of physicians certifying a large representative sample of deaths in Flanders, Belgium

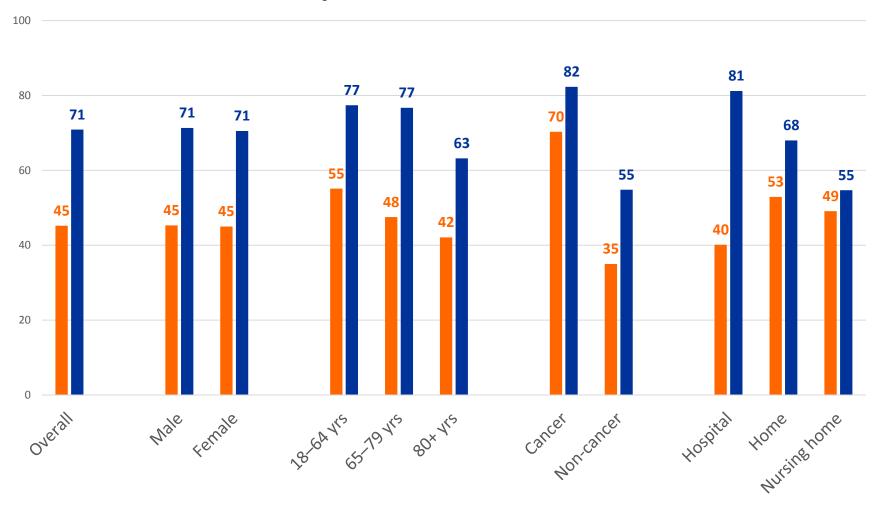
- Death certificates in first half of 2013 sampled at Flemish Agency for Care & Health (n=6871)
- Certifying physicians were sent questionnaire by mail about end-of-life decisions and care
- Intermediary third party (lawyer) to ensure anonymity
- Study and procedure approved by three independent bodies

Response rate: 60.6%

Questionnaire

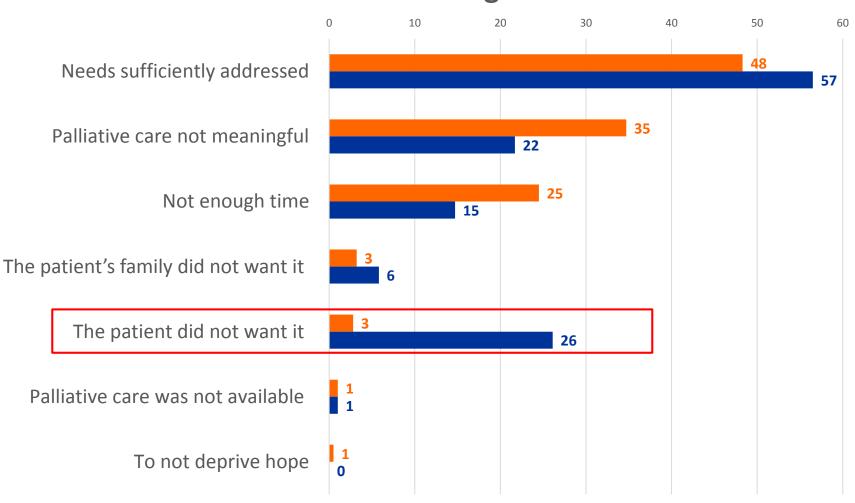
- Euthanasia: use of drugs with the explicit intention of hastening the end of life, at the patient's explicit request?
- Request for euthanasia that was not granted?
- Involvement of palliative care services in EOL care?
 - Palliative care support at home (multidisciplinary teams)
 - Hospital-based PC teams (mobile multidisciplinary teams)
 - Inpatient palliative care units (separate wards in hospital)
 - o Palliative reference person (nurse) in nursing home
- Reasons for not referring patient to PC?
- PC specialist consulted for euthanasia?
- Physician part of PC team?
- Death in PCU?

Involvement of palliative care services in EOL care



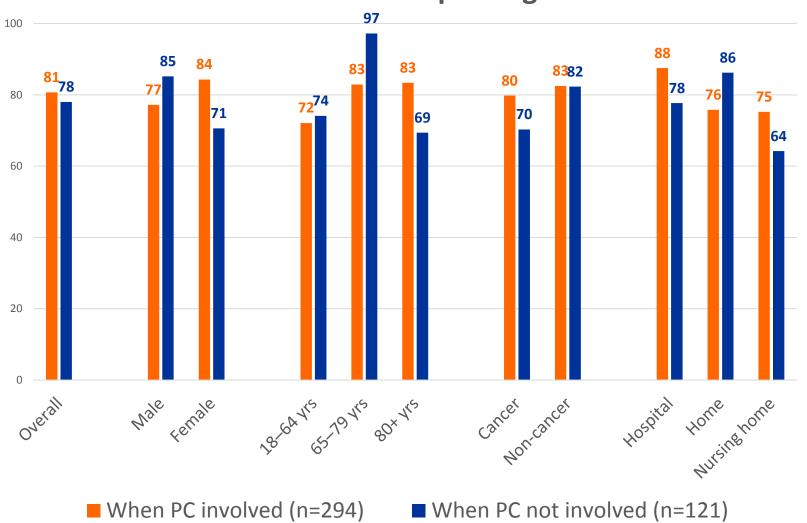
- % in deaths without euthanasia request (n=2042)
- % in deaths with euthanasia request (n=415)

Reasons for not referring to PC services

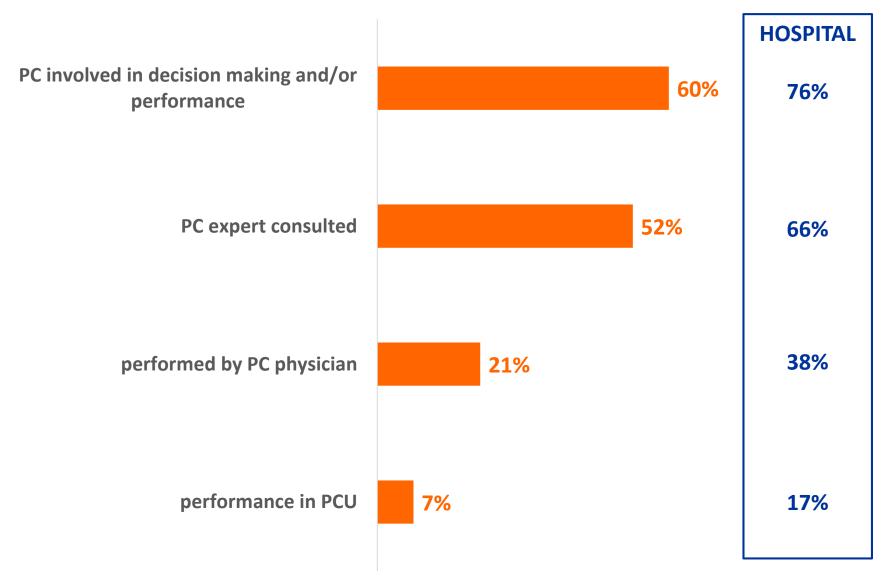


- % in deaths without euthanasia request (n=988)
- % in deaths with euthanasia request (n=126)





Role of PC in euthanasia (n=349)



Summary

Palliative care services were involved in the end-of-life care of 71% of those who requested euthanasia.

PC involvement is higher if a euthanasia request is voiced.

The likelihood of a request being granted was not lower in cases where palliative care was involved.

Palliative care professionals play a role in the euthanasia process in six out of 10 deaths by euthanasia, sometimes even performing euthanasia themselves.

Discussion

Significant involvement of PC in euthanasia practice in Flanders

- Contrary to international majority stance, not viewed as contradictory practices on the ground/at the bedside (=position Flemish Federation for Palliative Care)
- also found in the NL and Oregon (and Canada?): when regulated, PC gets involved

PC involvement higher in case of a euthanasia request. Chicken or the egg?

- Referral as reaction: called upon when euthanasia request is voiced
- PC as catalyst: involvement of PC in EOL care leads to euthanasia request

Discussion

PC involvement does not seem to reduce or "prevent" euthanasia

- Sign of widespread acceptance among PC clinicians
- Quid "PC abates euthanasia requests"?

On the palliative filter:

- In practice, many patients pass through the filter
- Doesn't have significant impact on outcome
- Still: not rare for patients to refuse referral OR for doctors to judge PC as futile: all "reasonable treatment options" explored?

Seemingly no lack of access to PC for people with a euthanasia request

Final observation

Palliative care associations are entitled to oppose legalisation of euthanasia BUT what if society decides to legalise anyway?

- Various possible degrees of involvement → contemplate implications of (middle) positions
- Wide variation in views among PC professionals → task of PC associations to strive for a pluralistic view?
- Medicine and health care in service of society: is it tenable to hold an autocentric view?