Fifty years of Euthanasia Practice in the Netherlands

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- No conflicts of interest to report.
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Outline

- The start of E/PAS in the Netherlands
- The present legal procedures and the practice
- Not foreseen effects and new developments
  - ‘Expertisecentrum Euthanasie’ (EE) and the first ‘dementia court case’ since 2002
- Comparing the Dutch practice with the BVG position paper

How did we get there?
Before and after the 1970-ies

- Before: no Dutch history on E/AS, unlike Germany, the UK, USA
- Since 1970: *fundamental value changes* in society:
  - paternalism vs self determination
  - More personal morality in sexual morality, drug use, the beginning and the en-of-life: abortion and dying
- *Emancipation, bottom up movements of societal change*

Dutch Euthanasia: the beginning

- 1. a hidden practice of euthanasia in the 70-ies
- 2. a *divided medical profession* aiming for (self-) regulation: E/PAS as *medical acts*
- 3. coming out in *full favour* of E/PAS in 1984,
- 4. since 1974: a legal community focusing on ending *life not as a criminal act, but as a medical act*, to alleviate suffering
- 5. jurisprudence *focusing on medical ethics and medical science* (Dutch Supreme Court)

From: Opposition/division to cooperation/ integration

- 6. a *divided political body*: Christian democrats versus liberals, undecided socialist party
- 7. an *inability* to bring the issue to parliamentary vote, a yearn for *pacification*
- 8. decide to *de-politicize the issue* by starting **national research on medical decisions at the-end-of-life** in 1990 (Remmelink Committee)

Towards regulation: bottom-up

- 9. develop guidelines to *regulate an existing practice* through conditions and evaluations from 1990 through 1997
- 10. introducing safeguards > 1997: *mandatory medical consultations* befóre the act and a *review by Euthanasia Review Committees* àfterwards of each individual case
- 12. The Committees *place prosecution at a distance,* consist of a lawyer, physician, ethicist
- 13. *develop a law thirty years after jurisprudence* with a liberal/socialist parliamentary majority, effective April 1, 2002

Major promoting factors

- The 1984 decision to ***support the option of E/PAS by the medical profession***, followed by a rise in support by physicians (public pressure, decline of religion based opposition)
- The ***cooperation*** between the legal institutions (in court cases), the state and the medical profession in policy development > 1997
- The **condition to limit E/PAS within a doctor-patient relationship/medical disease**. Effect: most cases are in primary care, >80%, <20% elsewhere
- The decision to put criminal law 'at a distance' of the euthanasia practice

Definitions in the Netherlands

- **Euthanasia**: ending some one's life at his request, the physician ends life by iv infusion/injection (voluntary active E)
- **Physician-Assisted Suicide**: helping some one to end life after a request : the patient ends life by drinking a potion, handed over by the physician (assisted suicide)

- **Euthanasia and assisted suicide are still crimes in the Dutch Criminal Code, unlike Germany**
- **But: in medicine and law both procedures are allowed, a preference is for PAS, however most cases, > 90%, are 'euthanasia'**

The present legal procedures: Euthanasia Law of 2002

- *Art. 2.1: Physician centered*! No prosecution **after mandatory reporting**, *if the physician holds the conviction that:*
  - 1. There is a voluntary and well considered request
  - 2. There is unbearable and hopeless suffering
  - Further:
  - 3. the patient is fully informed
  - 4. there are no reasonable alternatives for both patient and physician
  - 5. There is an independent collegial consultation
  - 6. ending life is with *due care, with prescribed means*
- Codification of cooperation between law and medicine

In addition: **advance directive**, art.2.2, for **incompetent patients**

- 'If the patient is > 16 years and no longer capable to express his will, but prior to this condition was deemed to have a reasonable understanding of his interests and has made a written statement containing a request for termination of life, the physician may carry out this request. The requirements of due care, referred to in the first paragraph, apply *mutatis mutandis*.'
- **A political addition and source of friction ever since, especially in case of incompetence for 'Alzheimer'**

Strong points: safeguards: 8

- 1. *the independent consultation before the act*, a sort of examination to protect the physician, a RDMS based group of consultants called SCEN: Support Consultation Euthanasia Netherlands
- 2. the **5 *Euthanasia Review Committees***: reviewing each individual case, but: show flexibility to social/medical changes in indications
- 3. Have ***national reviews*** every 5 years on all MDELs, including the E/PAS figures, procedures and policies

Effects of a ‘young practice’ > 2000

- Changes in numbers over the years

Developments in numbers of MDELs: 1990-2015

Medical Decisions at the End-of-Life	1990 %	2015%
Euthanasia	1,7	4,5
Physician-Assisted Suicide	0,2	0,1
Life Ending Action without Explicit Request (LAWER)	0,8	0,3
Dying in the course of Alleviating Pain and Suffering (APS)	19	39
Dying due to Non Treatment Decisions NTD	18 Total: ± 40%	17
Dying after Terminal Sedation		18 Total: ± 80%
REPORTING	18%	81%

Development in numbers

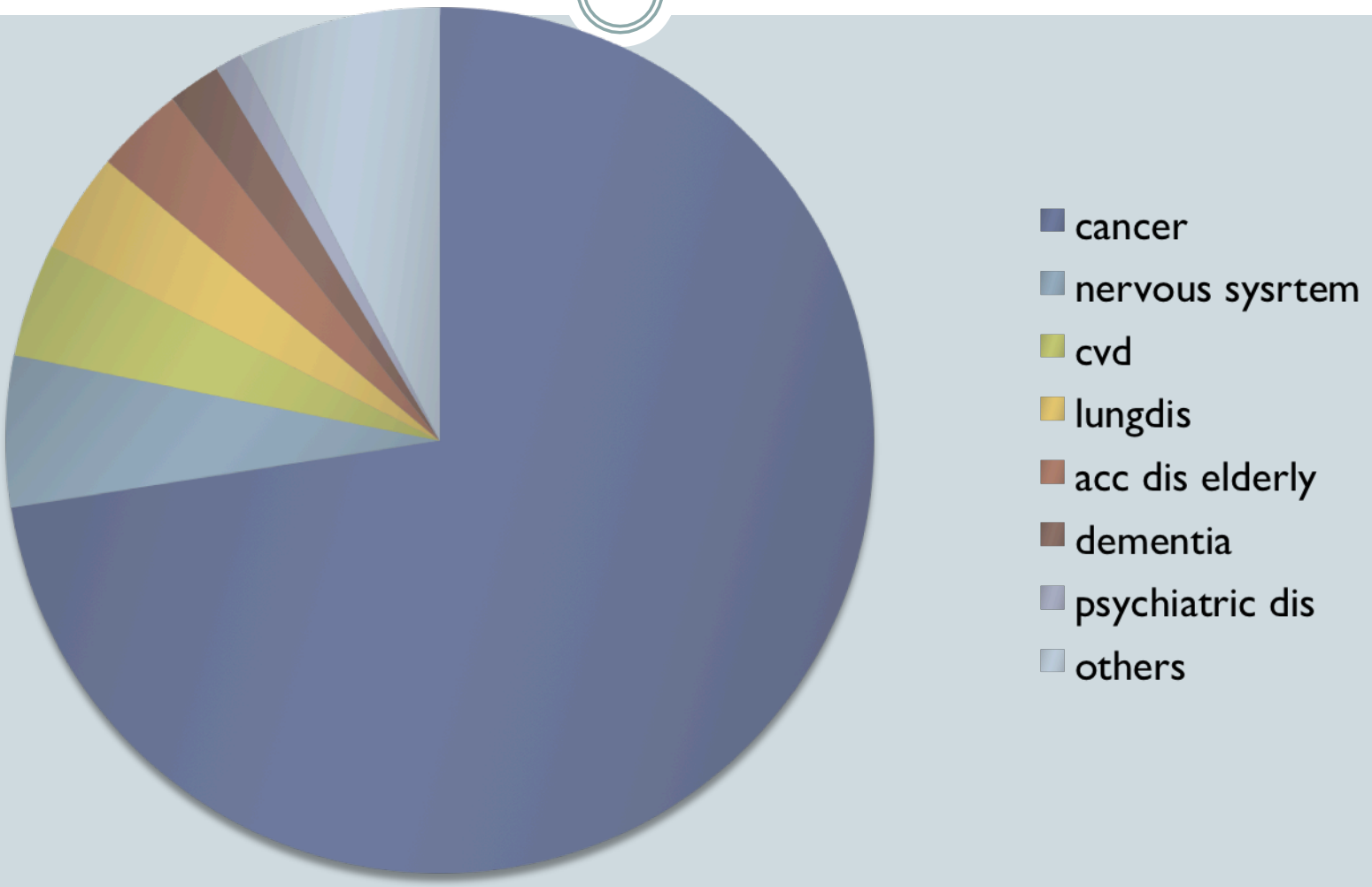
2007: ~2000

2012: ~4000

2017: ~6500

2020: ~7000

Diseases that qualify



Diseases in 2020: 6938

- Cancer: 4480: 65%
- Nerv system dis: 458: 6,6%
- Cardiac dis: 268: 3,8%
- Lungdis: 209: 3%
- Accumulation eld dis: 235: 3,3%
- Dementia: 168 and 2: 2,4% (92 Exp Euthanasie)
- Psych dis: 88: 1,2%,(68 von Expertisezentrum E)
- Combination of dis: 856: 12%
- Other diseases: 156: 2,5%

Unforeseen,but intended as possible: Expansion in indications for E/PAS

- 'Finding' the limits of the law: >2008: new indications
  - *psychiatric patients: often judged competent, conflict between still possible treatment options and autonomy of requesting patients*
  - *dementia patients: conflict about being able to affirm their advance directive when incompetent, between medical profession and pressure groups*
  - *'multiple ailments of the elderly': acceptance of severe loss of several functions being experienced as 'unbearable suffering'*
- Keep in Mind: ERCs only review what a group of physicians agrees on as acceptable assistance in dying

Developments/legal case High Council

- 1. **Organizing E/PAS 'outside'** a previous treatment relationship: the **Life Ending Clinic**: specialization/ institutionalization, *by physicians and nurses*
- 2. **Ideological developments**: attempts to realize E/ PAS for persons wishing 'Dying with Dignity in Old Age', without a disease, without physicians (close to position of the BVG)
- 3. **Parliamentary liberal proposals** to realize that ideology, after ' a completed life'/'vollendetes Leben'
- 4. Criminal case of euthanasia for dementia patient

Life Ending Clinic (2012): now called: Expertisecentrum Euthanasie

- Initiated and founded by the Euthanasia Society, now an independent organization
  - 3 reasons: doctors' refusals 'on principle',' 'incorrectly refused patients' and resistance or refusals in case of 'complex requests': psychiatric, dementia patients and patients with 'several diseases of the elderly'
  - No 'clinic' but now >70 teams of a physician and a nurse, make 3 or 4 home calls before E/PAS
- In 2020: accounting for 12% (=899) of all 6938 cases, 68 of 88 psychiatric cases, 90 of 170 dementia cases
- ***Self-image as a progressive population-focused institution, and: some physicians support these shifts***

Criminal charges for the dementia case 2017-2020

- 2017: geriatric specialist of the EE ends the life of a end-stage Alzheimer patient after sedation in the coffee, overcoming resistance with physical force during the act.
- The ERC finds 'not careful' and reports: to the medical inspection (police) and then the legal office for criminal charges
  - ERC: 'not careful' because of 'unclarity' in the written statement, because the patient wanted to reserve the moment for E for herself, but not wishing institutionalisation
  - 'Not careful' because of uncertainty concerning her competency, the written 'request'for when? and a lack of final communication
  - 'Not careful' because the prior sedation was not professional, the resistance should have stopped the euthanasia procedure

Dementia case 2017-2020: professional correction court

- The written statement could not have been leading to E/PAS given the reservation of the personal choice for ‘the moment’: no interpretation possible
  - No tried prior dialogue with the patient
  - No duty to persist in ending life without cooperation of the patient
  - The physical resistance during ‘the act’ not necessarily should have been interpreted as resistance rather than a scare reaction

Dementia case 2017: lower court proceedings

- The prosecution charge was ‘murder’
- The Court concluded that:
  - The request for E rested with the nursing home physician after being admitted against her will, with a demand to be helped to die when admitted
  - Her incompetency made her statements about ‘not yet’ irrelevant
  - Ergo: the physician could follow her ‘written requests’
- Leading to the Dutch High Council’s appreciation of arguments of the case ‘in the interest of law’

Dutch High Council's judgment

- The Council concluded that:
  - Both ERC and professional courts have based their decisions too much on *the literal interpretation of 'written statements' vs the* ***intentions of the patients,*** expressed to others/family members (against the professional courts)
    - > legal interpretation versus narrative concepts
  - Against the Lower Court's decisions: in case of incompetence to communicate: the intentions count
    - Communication should be tried however
  - For the assessment of uncertainty on 'unbearable suffering' specially trained experts need to be consulted
    - Focus on the difficulties to assess suffering with Alzherimer's
  - Sedating the patient before 'the procedure' is not unprofessional
    - Taking an unprecedented step inside medical ethics

Comparing the Dutch practice to the BVG statement

- The focus of the BVG is: personal autonomy, without specific medical/other conditions, probably leading to requests in- and outside of the medical domain
- Unbearable suffering vs no substantial limits, certainly not limited to medical diseases
- Not limited to the doctor-patient relationship vs open access on the basis of respecting personal autonomy

- Thank you for your interest.
- Gerrit K.Kimsma