Euthanasia and physician assisted suicide in the Netherlands

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Rijnstate Hospital Arnhem
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The context of euthanasia and physician assisted suicide in the Netherlands is one within the quality domains of palliative care
Palliative care team

José, Josien, Jolanda, Patricia, Joep
Sake, Gert-Jan, Jacques, Caro

Joep, Theo, Annemieke, Martin

Multidisciplinary hospital palliative care team (in-patient, out-patient)
Palliative care in hospitals

- Cancer
- Heart and lung diseases
- Frail elderly, dementia
Team quality consultation domains

- Structures and processes of care
- Physical aspects of care
- Psychological and psychiatric aspects of care
- Social aspects of care
Team quality consultation domains

- Spiritual, religious and existential aspects of care
- Cultural aspects of care
- Care of the imminently dying patient
- Ethical and legal aspects of care
- Loss, grief and bereavement aspects of care
Death

Disease modifying treatment

Phases of disease and illness

Diagnosis - e.g. bad news

Loss, grief and bereavement

The last 24-72 hours

Early integration of palliative care domains into disease modifying treatment

From tumor-orientation to symptom-orientation

Time
Euthanasia (E) and physician assisted suicide (PAS) in the Netherlands

Henk Landa (65 yrs) case history

Patient and family permission to show photographs
Medical history: summary (1/4)

- **Diagnosis:** carcinoma of the oesophagus (mid-thoracic) with at presentation metastases of the mediastinal lymph nodes, lungs and liver (stage 4)

- **Course:** transition to palliative care with on Henk’s request no invasive procedures such as laser treatment, brachytherapy and e.g. palliative chemotherapy
Medical history: summary (2/4)

- Physical symptoms:
  - Dysphagia (stricture)
  - Regurgitation (food) with sialorrhea
  - Anorexia and cachexia (CACS)
  - Retrosternal pain
  - Dyspnoea and productive cough (aspiration)
  - Hoarseness (laryngeal nerve involvement)
  - Weakness
Medical history: summary (3/4)

- Psychological symptoms:

  - Anxiety to suffocate (massive aspiration)
Medical history: summary (4/4)

- Level of independence: functionality

- Detoriation of condition with progressive (unbearable) symptom distress, including anxiety to suffocate

- Complete dependent on others (bedridden)

- Development not fitting with patient’s personhood
Patient and family: summary (1/2)

- Married with Alie (65 yrs) for more then 40 yrs
- 4 (married) children (26, 28, 30 and 35 yrs)
- Grandfather and grandmother of 8 grandchildren
- *Sound family dynamics and coalitions*
Patient and family: summary (2/2)

- Patient:
  - Successful entrepreneur
  - *High level of independence* (autonomy, decision making)
  - Family man
  - Marathon runner
The termination of life request

- Voluntary request in writing after due consideration, including results of several family meetings (other)

- High level of request
  stability over time

- After life review satisfied with
  the life already lived

- In a process of closure
  of life affairs
Unbearable suffering

- Unbearable suffering devoid of any hope (improvement)

- High level of (symptom) distress, including anxiety to suffocate

- Complete dependent on others (bedridden)

- Not fitting with personhood (autonomy, decision making, human dignity)

Outcome SOS V device high
Feelings and emotions

Role of physician and nurses: $A, B, C$ and $D$ of dignity conserving care
The *ABCD of dignity conserving care* at the EOL

- A = Attitude
- B = Behaviour
- C = Compassion
- D = Dialogue

*Healthcare providers have a profound influence on how patients experience illness and on their sense of dignity*

The consultation

- Formal (SCEN) *independent consultation* (physician) in accordance with request and unbearable suffering

- (SCEN project = Support Consultation Euthanasia [and Physician Assisted Suicide] the Netherlands)
E / PAS

- **Induction of coma** with 1500mg Thiopental sodium (Nesdonal) i.v. / 10 minutes

- **Induction of muscle relaxation** with 20mg Pancuronium dibromide (Pavulon) i.v. / 10 minutes
Review board E / PAS: due care

Special form independent physician (SCEN)

T.M.M. Klein Lankhorst-Visser, SCEN-arts
Lange Griet 31
6932MA Westervoort

Due care report

Consultvraag
- Arts: 1: andere euthanasie vraag
- Verpleegkundig: begeleiden team in deze situatie
- Patiënt/naasten: euthanasie vraag

Medicatieleist

Probleemmensuratisatie
- Lichamelijke aspecten:
  - hij ligt met linker been in tractie, is bediggeerig
  - pijn is met pijnmedicatie onder controle
- Psychologische aspecten:

In twee weken bedrust kan veel gebeuren: het had gekund dat ik na verloop van tijd wreef zou kunnen krijgen met mijn huidige situatie. Dit is echter niet gebeurd: ondanks veel positieve aandacht (bezoeken van familie, vrienden, collega's) blijft het verlies van mijn onafhankelijkheid een groot verdriet voor mij. De afhankelijkheid die ik nu heb is voor mij erg en ik had kunnen denken: hoewel ik zo veel mogelijk zelf probeer te doen, zijn er zaken waar ik wel hulp voor moet vragen (ontlasting etc.). Maar los daarvan verplichte de simpelste zaken mij om te bellen om hulp: als ik een pothoed van kastje stoot moet ik al de verpleging om hulp vragen.

Living will
Closure

Trajectory of follow-up care after 6 weeks
Inside the review board
Inside information from the review board
euthanasia / physician assisted suicide
(physician, ethicist and lawyer)

Annual report
2009
Content

- Statistical data
- Starting points for review
- Special points of interest
- Observations
- Procedure euthanasia
  review board (optional)
Content

- Statistical data
- Starting points for review
- Special points of interest
- Observations
- Procedure euthanasia review board (optional)
<table>
<thead>
<tr>
<th>Year</th>
<th>Number</th>
</tr>
</thead>
<tbody>
<tr>
<td>1999</td>
<td>2216</td>
</tr>
<tr>
<td>≈</td>
<td>≈</td>
</tr>
<tr>
<td>2003</td>
<td>1815</td>
</tr>
<tr>
<td>≈</td>
<td>≈</td>
</tr>
<tr>
<td>2007</td>
<td>2120</td>
</tr>
<tr>
<td></td>
<td>(willingness to report almost 100%)</td>
</tr>
<tr>
<td>≈</td>
<td>≈</td>
</tr>
<tr>
<td>2009</td>
<td>2636</td>
</tr>
</tbody>
</table>

Source: Annual reports review board E / PAS the Netherlands
<table>
<thead>
<tr>
<th></th>
<th>Number</th>
<th>%</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>E vs PAS vs combination</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td><strong>E</strong></td>
<td>2443 / 2636</td>
<td>92,7</td>
</tr>
<tr>
<td><strong>PAS</strong></td>
<td>156 / 2636</td>
<td>5,9</td>
</tr>
<tr>
<td><strong>Combination</strong></td>
<td>37 / 2636</td>
<td>1,4</td>
</tr>
</tbody>
</table>

Source: Annual report 2009 review board E / PAS the Netherlands
### Statistical data (3/5)

<table>
<thead>
<tr>
<th>Disease / year</th>
<th>1999</th>
<th>≈</th>
<th>2009</th>
</tr>
</thead>
<tbody>
<tr>
<td>Cancer</td>
<td>90,3 %</td>
<td>≈</td>
<td>81,7 %</td>
</tr>
<tr>
<td>Diseases of the nervous system</td>
<td>2,3 %</td>
<td>≈</td>
<td>5,0 %</td>
</tr>
<tr>
<td>Diseases of the lung</td>
<td>2,3 %</td>
<td>≈</td>
<td>5,5 %</td>
</tr>
<tr>
<td>Cardiovascular diseases</td>
<td>1,6 %</td>
<td>≈</td>
<td>2,0 %</td>
</tr>
<tr>
<td>AIDS</td>
<td>0,3 %</td>
<td>≈</td>
<td>0,2 %</td>
</tr>
<tr>
<td>Other diseases</td>
<td>3,2 %</td>
<td>≈</td>
<td>5,6 %</td>
</tr>
</tbody>
</table>

Source: Annual report 1999 / 2009 review board E / PAS the Netherlands
## Statistical data (4/5)

<table>
<thead>
<tr>
<th>Year / physician</th>
<th>General physician</th>
<th>Specialist</th>
<th>Nursing home physician</th>
<th>Other disciplines</th>
</tr>
</thead>
<tbody>
<tr>
<td>1999</td>
<td>1875/84,6 %</td>
<td>296/13,4 %</td>
<td>44/2,0 %</td>
<td>1/-</td>
</tr>
<tr>
<td>2009</td>
<td>2117 / 80,3 %</td>
<td>170 / 6,5 %</td>
<td>188 / 7,1 %</td>
<td>6,1 % (hospice 4,7 %)</td>
</tr>
</tbody>
</table>

Source: Annual report 1999 / 2009 review board E / PAS the Netherlands
### Statistical data (5/5)

<table>
<thead>
<tr>
<th>2005: EOL decision making</th>
<th>Number</th>
<th>%</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>E / PAS / combination</strong></td>
<td>1933 / 136,000</td>
<td>1.4</td>
</tr>
<tr>
<td><strong>PS</strong></td>
<td>11,150 / 136,000</td>
<td>8.2</td>
</tr>
</tbody>
</table>

Several Dutch government reports / 5-yr surveys death register
Summary

- Mainly used in patients with cancer (≈85%)
- More or less the domain of the general physician (≈80%)
- Willingness to report almost complete (≈95%)
- Figures (annual cases) show increase over time
- E (≈90%) outrange PAS
- E / PAS 1,4% of EOL decision making (2005)
Content

- Statistical data
- Starting points for review
- Special points of interest
- Observations
- Procedure euthanasia review board (optional)
Starting points for review *afterwards*

- Unbearable suffering devoid of any hope
- Voluntary request after due consideration
- Consultation
- The action (execution)
- Conclusion
- Scope for personal comments review board
Formal opinion euthanasia / physician assisted suicide review board

- Procedure (law)
- Facts and circumstances
  - Nature of (unbearable) suffering, (level of) information provision and (discussed) alternatives
  - (Stability) of termination of life request
  - (Independent) consultation (level of concordance)
  - The action (execution)
- Review (summary)
- Decision
**Due care requirements** to be examined and / or taken into account by the physician

- A voluntary request after due consideration, preferably of a lasting nature (request stability)

- Long-lasting, unbearable suffering devoid of any hope (perspective)
Due care requirements to be examined and / or taken into account by the physician

- Prior consultation with an independent (experienced) physician
- Proper reporting
Due care requirements to be examined and / or taken into account by the physician

- Consulting other care providers (e.g. nurses) involved in the case

- Preventing unnecessary suffering among the family (and friends)
**Due care requirements** to be examined and / or taken into account by the physician

- The physician is present and / or can be reached (PAS)
- Acting with due care from a medical-technical perspective
Content

- Statistical data
- Starting points for review
- Special points of interest
- Observations
- Procedure euthanasia
  review board (optional)
A voluntary request after due consideration, preferably of a lasting nature

- Explicit and specific request by the patient himself/herself, preferably in writing
- No room for assumed permission
- Attention for communication, information and determining a patient’s living will (advance directives)
Long-lasting, *unbearable suffering* devoid of any hope

- The requirement of due care is at the center of the debate on euthanasia / physician assisted suicide

- Attention is paid to subjectivity, objectivity and the real treatment prospects of the suffering, both somatic and / or psychological (e.g. SOS V device)

- Knowledge, attitude and skills regarding palliative care
### Review board E / PAS results 13-08-2008 (33 cases)

<table>
<thead>
<tr>
<th>Report number</th>
<th>Medical signs and symptoms</th>
<th>Loss of function</th>
<th>Personal aspects: self-appraisal, loss of independence</th>
<th>Aspects of social environment</th>
<th>Total number</th>
</tr>
</thead>
<tbody>
<tr>
<td>242;244;246;251;256;257;258;259;260;265</td>
<td>+</td>
<td></td>
<td></td>
<td></td>
<td>10</td>
</tr>
<tr>
<td>233;234;238;241;243;254;261;266</td>
<td>+</td>
<td></td>
<td>+</td>
<td></td>
<td>8</td>
</tr>
<tr>
<td>235;239;245;248;252;253</td>
<td>+</td>
<td>+</td>
<td></td>
<td></td>
<td>6</td>
</tr>
<tr>
<td>236;237;255;263</td>
<td>+</td>
<td>+</td>
<td>+</td>
<td></td>
<td>4</td>
</tr>
<tr>
<td>249;250;264</td>
<td></td>
<td></td>
<td>+</td>
<td></td>
<td>3</td>
</tr>
<tr>
<td>240</td>
<td>+</td>
<td></td>
<td>+</td>
<td>+</td>
<td>1</td>
</tr>
<tr>
<td>262</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td>Not evaluable</td>
</tr>
</tbody>
</table>

Source: Joep Douma (E / PAS review board) SOS V evaluation
Prior consultation with an independent physician

- Independent with respect to patient, close relatives and attending physician

- A counselor with expertise in this field (SCEN project: Support and Consultation in case of Euthanasia and assisted suicide in the Netherlands)

- Attention is paid to divided consultation, differences of opinion and reporting
**Reporting**

- Obligation to keep a file in accordance with the Medial Treatment Agreement Act

- Reporting must provide detailed information on the existing requirements of due care

- Reporting must form a basis for accountability
Consulting other care providers involved in the case

- In general of special significance in the stage when views are formed

- Useful and desirable within the context of putting together a comprehensive file

- Care providers keeping a file of their own may be useful
Preventing unnecessary suffering among the family

- Striving towards consensus of feelings
- The patient’s right to privacy prevails
- Attention is paid to the follow-up interview
Acting with due care from a medical-technical perspective and a physician who is present / can be reached

- KNMP euthanatica guideline (Dutch society of pharmacists)
- Consultation with pharmacist desirable
- Special attention paid to assisted suicide (presence / ability to be reached)
Content

- Statistical data
- Starting points for review
- Special points of interest
- Observations
- Procedure euthanasia
  review board (optional)
Observations regarding review of due care requirements

- Overtime request stability sometimes unclear

- Extent of suffering is sometimes difficult to assess

- Quality of palliative care applied not always clear (e.g. communication skills, dealing with emotions, shared-decision-making, health care ethics [consultation])
Observations regarding review of due care requirements

- Consultation is not always convincing. SCEN project stands for a major improvement (Support and Consultation in case of Euthanasia and physician assisted suicide in the Netherlands)

- Sometimes keeping a file leaves something to be desired (reporting)
Observations regarding review of due care requirements

- The action (execution) not very consistent

- Extent to which physician can be reached (assisted suicide) not always well organized

- Trajectory surrounding follow-up care (e.g. family, friends and caregivers) unknown (no obligation)
Practical information and points of interest / the action (execution)

- Induction of coma with Thiopental sodium (Nesdonal) 20mg/kg in NaCl 0.9% i.v. (1-2g)

- Induction of muscle relaxation with Pancuronium dibromide (Pavulon) 0.3mg/kg in NaCl 0.9% i.v. (16-24mg)
Practical information and points of interest / the action (execution)

- Mixtura nontherapeutica pentobarbitali
  9g/100ml (liquid)
**Formal opinion** euthanasia / physician assisted suicide review board

- Procedure (law)
- Facts and circumstances
  - Nature of (unbearable) suffering, (level of) information provision and (discussed) alternatives
  - (Stability) of termination of life request
  - (Independent) consultation (level of concordance)
  - The action (execution)
- Review (summary)
- Decision
## Palliative sedation versus E / PAS

<table>
<thead>
<tr>
<th></th>
<th><strong>Palliative sedation</strong></th>
<th><strong>Euthanasia / PAS</strong></th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Aim</strong></td>
<td>Treatment of refractory symptoms, lowering consciousness</td>
<td>Death</td>
</tr>
<tr>
<td><strong>Decision process</strong></td>
<td>Consensus (caregiver) [not always possible, emergency], no second opinion, no board review</td>
<td>Request (patient) [consensus], unbearable suffering, second opinion, carrying out, board review</td>
</tr>
<tr>
<td><strong>Shortening of life</strong></td>
<td>No</td>
<td>Yes</td>
</tr>
<tr>
<td><strong>Reversible</strong></td>
<td>Yes</td>
<td>No</td>
</tr>
<tr>
<td><strong>Drug(s)</strong></td>
<td>Midazolam, Levomepromazine</td>
<td>Thiopental sodium, Pancuronium dibromide, Mixtura pentobarbitali</td>
</tr>
<tr>
<td><strong>Dosage(s)</strong></td>
<td>NA</td>
<td>NA</td>
</tr>
<tr>
<td><strong>Administering</strong></td>
<td>Preferably subcutaneous, pump</td>
<td>Intravenous, orally</td>
</tr>
</tbody>
</table>
Thank you for your attention

Multidisciplinary hospital palliative care team (in-patient, out-patient)

José, Josien, Jolanda, Patricia, Joep
Sake, Gert-Jan, Jacques, Caro

Joep, Theo, Annemieke, Martin