Ethical Issues in Neurological Palliative Care

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Outline

1. End-of-life decisions
2. Ethical criteria
3. Practical problems
4. Wish to hasten death
End-of-life decisions

- **General population:**
  Two thirds of deaths are foreseeable
  23-50%: decisions to allow death to occur
  *Van der Heide A et al, Lancet 2003*

- **Intensive care:**
  50-90% of deaths based on decision to let die
  *Sprung CL et al, JAMA 2003*
  *Vincent JL et al, Chron Respir Dis 2004*

- **Palliative care:**
  70% of deaths based on decision to let die
  *Schildmann J et al, Palliat Med 2010*
Globally leading causes of death (2008)

<table>
<thead>
<tr>
<th>High-income countries</th>
<th>Deaths in millions</th>
<th>% of deaths</th>
</tr>
</thead>
<tbody>
<tr>
<td>Ischaemic heart disease</td>
<td>1.42</td>
<td>15.6%</td>
</tr>
<tr>
<td><strong>Stroke and other cerebrovascular disease</strong></td>
<td><strong>0.79</strong></td>
<td><strong>8.7%</strong></td>
</tr>
<tr>
<td>Trachea, bronchus, lung cancers</td>
<td>0.54</td>
<td>5.9%</td>
</tr>
<tr>
<td><strong>Alzheimer and other dementias</strong></td>
<td><strong>0.37</strong></td>
<td><strong>4.1%</strong></td>
</tr>
<tr>
<td>Lower respiratory infections</td>
<td>0.35</td>
<td>3.8%</td>
</tr>
<tr>
<td>Chronic obstructive pulmonary disease</td>
<td>0.32</td>
<td>3.5%</td>
</tr>
<tr>
<td>Colon and rectum cancers</td>
<td>0.30</td>
<td>3.3%</td>
</tr>
<tr>
<td>Diabetes mellitus</td>
<td>0.24</td>
<td>2.6%</td>
</tr>
<tr>
<td>Hypertensive heart disease</td>
<td>0.21</td>
<td>2.3%</td>
</tr>
<tr>
<td>Breast cancer</td>
<td>0.17</td>
<td>1.9%</td>
</tr>
</tbody>
</table>
Capacity to decide for yourself

Existential weight of the decisions

Course of life-limiting diseases

Rise of guardianship cases per year in Germany

Guardianship cases 1995-2009 (official statistics)
1. End-of-life decisions

2. Ethical criteria

3. Practical problems

4. Wish to hasten death
Shifting the goal of care

Integrated Therapy (curative + palliative)

Rehabilitation

Life support

Palliation

End-of-life care

Bereavement care

Adapted from Murray SA et al (2005) BMJ
What is the patient’s preferred goal of treatment?

Are there realistic chances to achieve this goal?

Does the benefit of this goal outweigh the risks and burdens associated with the intervention required to achieve the goal?
- Assessment by the physician
- Recommendation and deliberation with patient
- Assessment by the patient

Perform intervention and review it regularly
Ethical criteria

Therapy

Best interests

Informed Consent

Wellbeing

Autonomy
1. End-of-life decisions

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Assessing best interests

- Requires judgment about current and anticipated quality of life of the individual patient
- Quality of life is primarily subjective

→ Prognosis in neurology often unclear
→ difficult to assess in neurological patients with communication barriers
→ questionable in patients with disorders of consciousness

Owen AM et al. Science 2008
Uncertainty regarding mental state

<table>
<thead>
<tr>
<th>I think patients with this diagnosis are able to:</th>
<th>Vegetative state (n=132)</th>
<th>Minimally conscious state (n=148)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Be aware of themselves</td>
<td>9</td>
<td>54</td>
</tr>
<tr>
<td>Be aware of surroundings</td>
<td>6</td>
<td>57</td>
</tr>
<tr>
<td>Interact with others</td>
<td>8</td>
<td>57</td>
</tr>
<tr>
<td>Have thoughts</td>
<td>23</td>
<td>72</td>
</tr>
<tr>
<td>Have emotions</td>
<td>35</td>
<td>87</td>
</tr>
<tr>
<td>Experience hunger/thirst</td>
<td>46</td>
<td>92</td>
</tr>
<tr>
<td>Feel touch</td>
<td>67</td>
<td>94</td>
</tr>
<tr>
<td>Feel pain</td>
<td>77</td>
<td>96</td>
</tr>
</tbody>
</table>

Kuehlmeyer K et al. J Neurol 2012
Controversy among physicians

Surveys among physicians:
May withdrawing artificial nutrition and hydration in the persistent vegetative state be ethically justified?

- USA: 89%  
- UK: 94%  
  Grubb et al, Lancet 1996
- Belgium: 94%  
- Germany: 46%  
  Kuehlmeyer et al 2012
- Italy: 66%  
  Solarino et al, Intensive Care Med 2011
- Europe: 73% Northern Europe
  70% Central Europe
  55% Southern Europe  
  Demertz et al, J Neurol 2011

→ Religion is main determining factor  
  Demertz 2009 and 2011
Currently expressed will of a competent and informed patient

If not present

Anticipatorily expressed will (advance directives)

If not present

Substituted judgment (presumed will)

If not possible

Behavioral expressions of will
Common examples

**Dementia patients:**
- Refusal of nutrition (turning head, closing mouth)
- Physical defence against nurses, pulling PEG tube
- Smiling, laughing, crying, moaning

*Kuehlmeyer K et al. (in preparation)*

**Severely brain-injured patients:**
- Complex reflex movements
- Autonomic reactions (sweating, tachycardia…)
- Survival of critical situation
Study on surrogate decision making by guardians and relatives of dementia patients:

Current behavior
Prior statements
Nurses' view
Physician's view
Family's view
Life attitude

Relative decisional weight (0-1)

Jox RJ et al. (2012) Int J Geriatr Psychiatr
Factors for treatment decisions about dementia patients (survey of nurses in German care homes):

Kuhelmeyer K et al (in preparation)

- Patients’ behavior
- Patients’ wellbeing
- Advance directives
  - Medical indication
  - Law
  - Relatives
  - Guilt
  - Own values
- Resources
- Guidelines
- Authority

Kuhelmeyer K et al (in preparation)
Ethical appraisal

- Non-verbal behavior is often *situational and context-dependent*

- Expresses the *current state of wellbeing*, but not an autonomous treatment decision

- Should be carefully *interpreted* and taken into account if *reliable and consistent* with patient’s personality

- May render an *advance directive* inapplicable if the clinical situation is different from the one anticipated
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Current Case

- Tony Nicklinson (UK), 58 years old
- Stroke 2005 → locked-in syndrome
- Asked court to allow his doctor to assist in suicide or perform euthanasia

“My life can be summed up as dull, miserable, demeaning, undignified and intolerable (...) Why should I be denied a right, the right to die of my own choosing, when able-bodied people have that right and only my disability prevents me from exercising that right?”

- Highest court rejected claim (delegates to parliament)
- Tony refuses to eat & drink, dies 6 days later
Prospective questionnaire study of 66 ALS patients and 62 primary caregivers (Germany & Switzerland)

50% of patients could imagine asking for the physician to assist in suicide

14% expressed current wish to hasten death (correlated with depression, anxiety, loneliness, low QoL)

Attitudes stable over 13 months

None talked to physician about it, yet 50% would like to

Stutzki R et al. Amyotroph Lateral Scler (in press)

Data from Oregon show:

- 25% of patients who wish to hasten death have depression
- 33% of patients do not use the prescribed drugs
- No loss of trust towards physicians
- No increased depression or complicated grief in relatives
- No slippery slope towards vulnerable groups
- Regulation improved palliative care

Battin MP, JME 2007 Ganzini L, J Pain Symptom Manage 2009*
Thank you for the attention!

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