The limits of consciousness

DEATH, FROM CELLS TO SOCIETIES: AGEING, DYING, AND BEYOND
JOURNÉES THÉMATIQUES 2018
ECOLE DE L’INSERM LILIANE BETTENCOURT

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Pr Steven LAUREYS, MD, PhD
1. Consciousness & altered states of consciousness
2. Brain death
3. Unresponsive Wakefulness Syndrome
4. Ethics of death and dying
5. Near-Death Experience
6. Conclusion
1. Consciousness and altered states of consciousness
A definition of consciousness
Reducing consciousness to 2D

Unresponsive Wakefulness Syndrome – a new name for the vegetative state

Bodart & al, Semin Neurology, 2013 ; Gosseries et al., The Open Neuroimaging Journal, 2016 ; Laureys & al. BMC Medicine, 2010
2. Brain Death
“I am dead”

Charland-Verville and al., Cortex, 2013

Blue = hypometabolic areas
"I am not dead"

Mechanical Ventilation

Bjørn Ibsen – Copenhagen 1952

Pius XII – Vatican 1957

Laureys, Nature Reviews Neuroscience, 2005
Clinical death ≠ death

Since the 50’s, no one with the criteria of brain death ever recovered consciousness.

Transplants - Are the donors really dead?

Laureys, Nature Reviews Neuroscience, 2005
Brain death = death

NORMAL CONSCIOUSNESS

BRAIN DEATH

The hollow-skull sign

Laureys, Nature Reviews Neuroscience, 2005
8 criteria’s of brain death

- Demonstration of coma
- Evidence for the cause of coma
- Absence of brainstem reflexes
- Absence of motor responses
- Apnea
- Absence of confounding factors,
- A repeat evaluation after 6 h is advised
- Confirmatory laboratory tests are only required when specific components of the clinical tests cannot be reliably evaluated

Death: event or process?

Death donor rule

- Patient must be declared dead before any organ removal
  - No matter the state of the person
  - No matter how much good it could do

- Even if there is a lack of donors ...

- Depends on the definition of death ...

Neocortical death myth

Death = permanent cessation of “higher functions of the nervous system that demarcate man from the lower primates”

→ Could include UWS patients as well as MCS patients!

1. Incomplete understanding of consciousness

2. Clinical tests would require the provision of bedside behavioural evidence

3. Complimentary tests for neocortical death

4. Proving irreversibility is key to any concept of death

Laureys, Nature Reviews Neuroscience, 2005
Prognosis in Non Traumatic Patients

First diagnosed as Unresponsive Wakefulness Syndrome (UWS)

First diagnosed as Minimally Conscious State (MCS)

Cassol et al, in preparation
3. Unresponsive Wakefulness Syndrome
UWS ≠ brain dead

- UWS: wakefulness with no signs of awareness
- Both terms are all often mixed up in the lay — and even medical — press.
- Payne & al. (1996) showed that ...

US neurologists and nursing home directors believed that UWS patients could be declared dead!

The case of Terri Schiavo
### Clinical & diagnostic differences

<table>
<thead>
<tr>
<th>Diagnosis</th>
<th>Eye opening</th>
<th>Breathing</th>
<th>Brainstem reflexes</th>
<th>Movements</th>
</tr>
</thead>
<tbody>
<tr>
<td>Brain Death</td>
<td>Within hours / days</td>
<td>No</td>
<td>With assistance</td>
<td>Altered generated by residual spinal activity</td>
</tr>
<tr>
<td>Irreversible UWS</td>
<td>3 Month (NTBI)</td>
<td>Spontaneously open</td>
<td>Spontaneously without assistance</td>
<td>Preserved</td>
</tr>
<tr>
<td></td>
<td>12 Month (TBI)</td>
<td></td>
<td></td>
<td>Much richer array of motor activity</td>
</tr>
</tbody>
</table>
Brain metabolism

Laureys, Nature Reviews Neuroscience, 2005
“More dead than dead ?”

- Dualism in consciousness: mind OR body / mind AND body ?

- Being in a persistent UWS < being dead
  - For themselves
  - For a family member

- Perception of mind as a persistent UWS < being dead
  - Persistent UWS are considered as a body > as a mind

- Alterlife beliefs and high religiosity +++

- Being in a persistent UWS = less than dead

4. Ethics of death and dying
Clinical context (1)

Gold standard = Behavioral assessment

Misdiagnosis ~ 40% without a standardized and validated tool

The Coma Recovery Scale – Revised

<table>
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<tr>
<th>Patient:</th>
<th>Date:</th>
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**AUDITORY FUNCTION SCALE**
- 4 - Consistent Movement to Command *
- 3 - Reproducible Movement to Command *
- 2 - Localization to Sound
- 1 - Auditory Startle
- 0 - None

**VISUAL FUNCTION SCALE**
- 5 - Object Recognition *
- 4 - Object Localization, Reaching *
- 3 - Visual Pursuit *
- 2 - Fixation *
- 1 - Visual Startle
- 0 - None

**MOTOR FUNCTION SCALE**
- 6 - Functional Object Use ¹
- 5 - Automatic Motor Response *
- 4 - Object Manipulation *
- 3 - Localization to Noxious Stimulation *
- 2 - Flexion Withdrawal
- 1 - Abnormal Posturing
- 0 - Non/Flaccid

**OROMOTOR/VERBAL FUNCTION SCALE**
- 3 - Intelligible Verbalization *
- 2 - Vocalization/Oral Movement
- 1 - Oral Reflexive Movement
- 0 - None

**COMMUNICATION SCALE**
- 2 - Functional: Accurate ¹
- 1 - Non-Functional: Intentional *
- 0 - None

**AROUSAL SCALE**
- 3 - Attention
- 2 - Eye Opening w/o Stimulation
- 1 - Eye Opening with Stimulation
- 0 - Unarousable

**TOTAL SCORE**

Schnakers et al., BMC Neurology, 2009; Gossseries et al., Brain Inj. 2014; Giacino et al., Neurology, 2002
Clinical context

- Electroencephalogram (EEG)
- Transcranial Magnetic Stimulation - EEG
- Magnetic Resonance Imaging (MRI)
- Positron Emission Topography (PET)

Clinical Misdiagnosis

First diagnosed as Unresponsive Wakefulness Syndrome (UWS)

First diagnosed as Minimally Conscious State (MCS)

Ethical implications

Attitudes towards end-of-life issues in disorders of consciousness: a European survey

Demertzi and al., *J Neurology* 2011 ; Gipson and al., *Neuroethics*, 2014
Pain Perception in Disorders of Consciousness: Neuroscience, Clinical Care, and Ethics in Dialogue


Treatment can be stopped in chronic...

(n=2259)

- ** Feel pain
- □ Do not feel pain

Demertzi & Racine and al., Neuroethics 2012
Proxy decision-makers (PDM)

- Generally family members
- High psychological distress
- Great physical and cognitive demands
- Struggling with the uncertainty and the grief

Meeker, *Qualitative health research*, 2004
Theoritically, how?

The way the PDM should act on behalf of the patient is a progressive one:

1. Wishes of the patient

2. Patients’ preferences based on their history and personal values

3. Objective markers that determine the patients’ best interest

Reasons to overrule patient wishes (1)

- **The expected recovery of the patient**
  1. Realists that understand the gravity of the situation and know that prolonged care for a patient in a UWS would be futile
  2. Procrastinators who were unsure or have heard of unexpected recoveries
  3. Fighters who were willing to sacrifice themselves for the patient and put trust in a miraculous recovery
  4. Family caregivers being ambivalent between hope, anticipatory grief and acceptance of the condition

Kuehlmeyer and al., *J Med Ethics*, 2012
Reasons to overrule patient wishes (2)

- The family definition of life sustaining treatment
  - Artificial Nutrition and Hydration ≠ medical intervention

- Moral obligation to not cause harm or pain
  - Fear of letting the patient starve to death

Kuehlmeyer and al., J Med Ethics, 2012
Influencing factors

- Personal characteristics and life circumstances
- Social network and interactions
- Communication and relationship with the clinician
- Relationship with patient
PDM’s and the healthcare providers

- Limited contact and discussions

- Quality of interaction suboptimal:
  - Vocabulary used: interfere with the understanding of info
  - Not enough emotional support

- Shared decision making > satisfaction from families

- Open communication even if uncertainty about the prognosis

Hyejin and al., *Nurs Ethics*, 2017
What about Exit MCS patient?

Female patient; Age = 58; 1 year post onset; Cardiac Arrest

One week hospitalisation: huge fluctuation in communication capacities

When asked if she was happy and wanted to live?
Say YES

When family is asked whether the patient would like to live in that state and what previously expressed?
Say NO

What would you do?
5. Near Death Experience
Vanhaudenhuyse and al, 2009 Yearbook of Intensive Care and Emergency Medicine Springer-Verlag
Brain death ≠ clinical death

Towards a neuro-scientific explanation of Near-Death Experiences?

Figure 4 – Number of publications per year on NDEs (for a total of 185 publications). Medline search performed in February 2018 with the keyword “near-death experiences”.

Martial, 2018, In Preparation
«I left my body»

Influence of etiology

Life-threatening “Real NDEs” n=140
Total score 16 ± 6 (7-30/32)

Non-life-threatening “NDE-like” n=50
Total score 17 ± 7 (7-30/32)
6. Conclusion
Take home message

- Different altered states of consciousness
- DEATH = BRAIN DEATH ≠ UWS
- Ethical issues
  - Diagnostic accuracy
  - End of Life decisions
- Making & promoting advance directives = help respect patient wishes
- Only proof of life after death is organ donation!
Thank you for your attention!

If you want more informations, contact:

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You lived a « near death experience » and want to testify?
Contact us!
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