Patients avec troubles de conscience
Comment on pense à leur prise en charge

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Definition clinique de la conscience

Conscious Wakefulness

Locked-in syndrome

Minimally Conscious State
- MCS+ (command following)
- MCS- (non-reflex movements)

“Vegetative”/unresponsive wakefulness syndrome

General Anesthesia

Coma

Deep sleep

Sleep St I-II

Drowsiness

Awake

= eyes opening

Awareness = command following

Attitudes | Neuroimaging | Conclusions

Demertzi et al, Encyclopedia of Consciousness 2009
Laureys, Trends in Cognitive Sciences 2005
From “how we ought to” to “how we think”: Opinions

Procedure

Questionnaire surveys
Scientific conferences and meetings in Europe
Binary outcome: Agree-Disagree

Study 1: Pain perception in DOC (n=2059)

Study 2: End-of-life in DOC (n=2475)

Study 3: Pain and end-of-life in DOC (n=2259)

Statistical Analysis (SPSS v.16)
Chi-square tests
Multiple Logistic Regressions
Proportion (medical, paramedical, other)
European region (Northern, Central, Southern)
Religiosity
Gender
Age

Demertzi et al. Désordres de la conscience : aspects éthiques
(1) Attitudes towards pain

Do you think patients in a ... can feel pain?

<table>
<thead>
<tr>
<th>Question Predictors</th>
<th>Odds Ratio</th>
<th>95% Confidence Interval</th>
<th>p value</th>
</tr>
</thead>
<tbody>
<tr>
<td>Do you think VS patients feel pain?</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Age</td>
<td>1.01</td>
<td>1.00 - 1.02</td>
<td>.050</td>
</tr>
<tr>
<td>Women</td>
<td>1.25</td>
<td>.99 - 1.58</td>
<td>.060</td>
</tr>
<tr>
<td>Northern Europe</td>
<td>1.00</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Central Europe</td>
<td>.81</td>
<td>.58 - 1.14</td>
<td>.240</td>
</tr>
<tr>
<td>Southern Europe</td>
<td>1.10</td>
<td>.76 - 1.60</td>
<td>.600</td>
</tr>
<tr>
<td>Paramedical professionals</td>
<td>1.56</td>
<td>1.20 - 2.00</td>
<td>&lt;.001</td>
</tr>
<tr>
<td>Religious respondents</td>
<td>1.37</td>
<td>1.10 - 1.70</td>
<td>.004</td>
</tr>
<tr>
<td>Do you think MCS patients feel pain?</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Women</td>
<td>2.38</td>
<td>1.33 - 4.26</td>
<td>.003</td>
</tr>
<tr>
<td>Religious respondents</td>
<td>1.83</td>
<td>1.05 - 3.18</td>
<td>.031</td>
</tr>
</tbody>
</table>

Predicted response: "agreement"

Demertzi et al, Progress in Brain Research 2009
(2) Attitudes towards end-of-life

VS is worse than death for
• patients: 55%
• families: 80%

MCS is worse than VS for
• patients: 54%
• families: 42%

Demertzi et al, Journal of Neurology 2011
(3) Attitudes towards pain & end-of-life

Treatment can be stopped in chronic...

- Feel pain
- Do not feel pain

<table>
<thead>
<tr>
<th>Agreement</th>
<th>VS/UWS</th>
<th>MCS</th>
</tr>
</thead>
<tbody>
<tr>
<td>0-20%</td>
<td>59</td>
<td>29</td>
</tr>
<tr>
<td>20-40%</td>
<td>77</td>
<td>38</td>
</tr>
<tr>
<td>40-60%</td>
<td>**</td>
<td>**p&lt;.001</td>
</tr>
<tr>
<td>60-80%</td>
<td>**</td>
<td>NS</td>
</tr>
<tr>
<td>80-100%</td>
<td>**</td>
<td>NS</td>
</tr>
</tbody>
</table>

Demertzi & Racine et al, Neuroethics 2012
Neural correlates of awareness?

Activation paradigms | Active paradigms | Resting state paradigms

Healthy | MCS | VS/UWS

Boly et al, Lancet Neurol 2008
Laureys et al, Neuroimage 2002

Imagine Tennis to answer 'YES'
Imagine Navigating to answer 'NO'

Monti & Vanhaudenhuyse et al, NEJM 2010
Owen et al, Science 2006

Demertzi & Antonopoulos, Brain in press
Demertzi & Gomez, Cortex 2014
Vanhaudenhuyse et al, Brain 2010
Physicians approve technology

The use of technology to get ancillary information about patients’ clinical status

- I think functional neuroimaging can differentiate between VS and MCS: 79%
- If a behaviorally VS patient would show normal activation on functional neuroimaging, this would change my diagnosis to the MCS: 83%
- I think invasive interventions are justified to diagnose and study disorders of consciousness or to provide prognostic information: 77%

The use of technology to develop treatments

- I think invasive interventions are justified to develop treatments for disorders of consciousness: 83%

The use of technology to assess conscious experiences

- Assuming surrogate informed consent, it is acceptable to do functional neuroimaging studies on perception of hunger and thirst in VS: 86%
- Assuming surrogate informed consent, it is acceptable to do functional neuroimaging studies on pain perception in VS: 81%
- Assuming surrogate informed consent, it is acceptable to do functional neuroimaging studies on perception of thirst in MCS: 80%
Que devons-nous aux patients TDC?

• The moral significance of Consciousness
  → ontological understanding: consciousness = personhood = moral agency
  → relational or contextual understanding: patients have value for others

• Legal challenges: responses to critical questions with technology

• Cognitive neuroscience is about brain/mind reading
  → to what degree do we neuroscientists have the right to interfere with a patient’s intimacy, such as cognitive contents, in the absence of their consent?
  → in essence, where do we draw the limits of deciphering another person’s cognitive content, like dreams, ongoing mentation etc? What is the additive value of it to a societal level?
Thank you!

The departments of Neurology and Radiology in Paris and Liège

...but mostly patients and their families!

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