Opinions of Stakeholders about Medico-Ethical Issues stemming from the Care of Patients with DOC

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Opinions about consciousness?

Functionnalism

Materialism

Dualism

A moment in the body of DOC patient
A life worth living as a Locked-in Syndrome patient

A moment in the life of a Locked-in Syndrome patient

**Conscious & Cogn**

![Graph showing continuity of self-image](image)

- LIS patients (n=44)
- Healthy controls (n=20)

**Interpersonal attitudes impact experienced personhood**

- N=30

![Bar chart showing attitudes](image)

- Lack of communication: 97%
- Objectification attitudes: 77%
- Lack of consideration: 63%

Nizzi et al, *Conscious & Cogn* 2012  
Nizzi et al., *NeuroEthics* 2018
Dualism in consciousness:
- Body AND Mind
- Body OR Mind

Being in a persistent Vegetative State < dead

Perception of the mind in persistent Vegetative State < dead
- persistent UWS: bodies > mind

Persistent Vegetative State = inferior state to death?

Payne & al. (1996):
American neurologists and nursing home directors thought that UWS patients could be considered dead!

Demertzi et al., Annu. N.Y. Acad. Sci, 2009; Gray et al., Science 2007; Gray et al., Cognition, 2011
What does my relative feel about pain...
Caregivers are ambivalent about pain perception in UWS

Do you think that patients in Unresponsive Wakefulness Syndrome can feel pain?

Demertzi et al, *Prog Brain Res* 2009
Caregivers endorse pain perception in the MCS

Do you think that patients in a Minimally Conscious State can feel pain?

Demertz et al, Prog Brain Res 2009
New ways to communicate? Promising tools

Brain-Computer Interface (BCI)

Functional MRI (fMRI)

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


- Monti et al., *New England J Med* 2010
Communication and decision-making

- BCI & fMRI = not adapted to all patients due to confounding factors

- Ethical dilemma – What about informed consent?

  - Need to ask the person whether she agrees or not?

  - Communication ≠ Informed decision making

Farisco et al., *Ethical issues in behavioral neuroscience*, 2015
How can we envision the future?

| On pain perception | On medical management | On needs and burden |

Cassol et al, *in preparation*

**TBI Prognostic**

- **UWS**
  - MCS
  - Dead
  - UWS

- **MCS**
  - EMCS
  - Dead
  - MCS

**Treatment**

- Thibaut et al, *Brain Inj* 2017
What Do You Think? ... about end-of-life?
End of life is supported more for the UWS

2,475 medical professionals

- UWS/VS is worth than death
  - Patients: 55%
  - Families: 80%

- MCS is worth than UWS/VS for
  - Patients: 54%
  - Families: 42%

Demertzi et al, Journal of Neurology 2011
End of life is supported less when pain perception is endorsed.

2259 medical and paramedical professionals

When VS/UWS patients do not feel pain

Legally, how the decision should be made?

1. **Advance directives** = written declaration made by a competent person in anticipation of his future incompetence, expressing the treatment preferences.

2. The **legal representative** has the right to take responsibility based on **patients expressed wishes**.
   - He / she must protect the interest of the patients according to the principles of beneficence and non-maleficence.

3. When the patient's wishes are not known, the legal representative should try to reproduce the **patient's preferences based on his / her personal history and values**.

4. When this is not possible, decisions should be based on more **objective markers**
   - Probability of recovery
   - Impact on family

Family burden

- High psychological distress
- Great physical and cognitive demands
- Struggling with the uncertainty and the grief
- Financial burden

Family needs in Locked-in Syndrome

- Honest answers to questions
- Information on rehabilitation progress
- Respect of needs and desires
- Getting external/institutional aide in case of caregiver’s absence
- Appease doubts and fears
- Help to preparing for the worth

Lugo et al. *Brain Inj.* 2017
What about DOC professional caregivers?

1/5 in burn-out

Table II. Percentage of burnout and its three sub-components among all participants.

<table>
<thead>
<tr>
<th></th>
<th>Low</th>
<th>Moderate</th>
<th>High</th>
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</thead>
<tbody>
<tr>
<td>Burnout</td>
<td>82%</td>
<td>15%</td>
<td>3%</td>
</tr>
<tr>
<td>Emotional exhaustion</td>
<td>67%</td>
<td>21%</td>
<td>12%</td>
</tr>
<tr>
<td>Depersonalization</td>
<td>64%</td>
<td>27%</td>
<td>9%</td>
</tr>
<tr>
<td>Accomplishment</td>
<td>3%</td>
<td>12%</td>
<td>85%</td>
</tr>
</tbody>
</table>

Table III. Percentage of healthcare workers presenting a burnout.

<table>
<thead>
<tr>
<th>Profession</th>
<th>Burnout</th>
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</thead>
<tbody>
<tr>
<td>Physician</td>
<td>8%</td>
</tr>
<tr>
<td>Nurse</td>
<td>24%</td>
</tr>
<tr>
<td>Nursing assistant</td>
<td>23%</td>
</tr>
<tr>
<td>Physio-speech/ergo-therapist</td>
<td>8%</td>
</tr>
<tr>
<td>Psychologist/social worker</td>
<td>10%</td>
</tr>
</tbody>
</table>

Gosseries et al. *Brain Inj.* 2012
1. Opinions are a priceless means of information for public policy makers

2. Consciousness carries a moral significance which can influence medical management

3. Family caregivers are in need of attention and potential treatment themselves
Thanks for your attention!

...but mostly patients and their families!

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