



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



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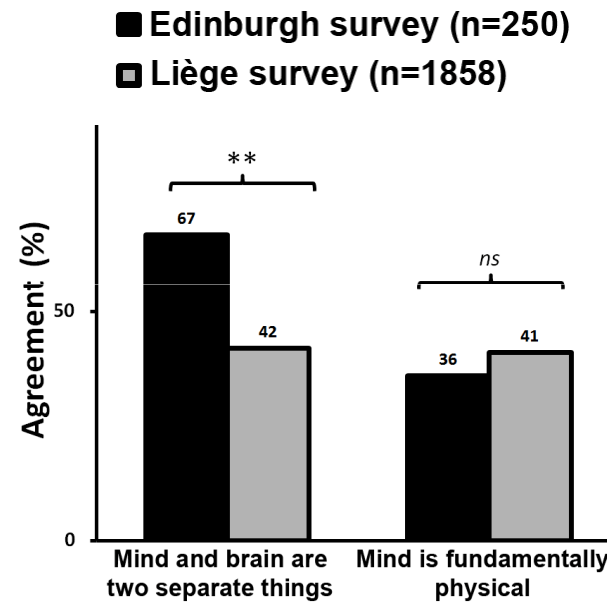
Naci lab, Trinity College Dublin,
Dublin - 02/05/2019

Opinions about consciousness ?

Functionnalism

Materialism

Dualism



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

A moment in the body of DOC patient



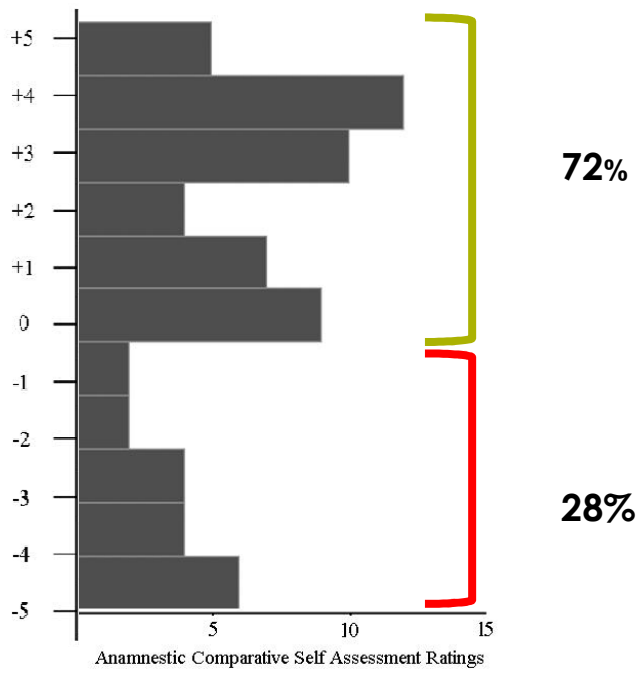


A life worth living as a Locked-in Syndrome patient



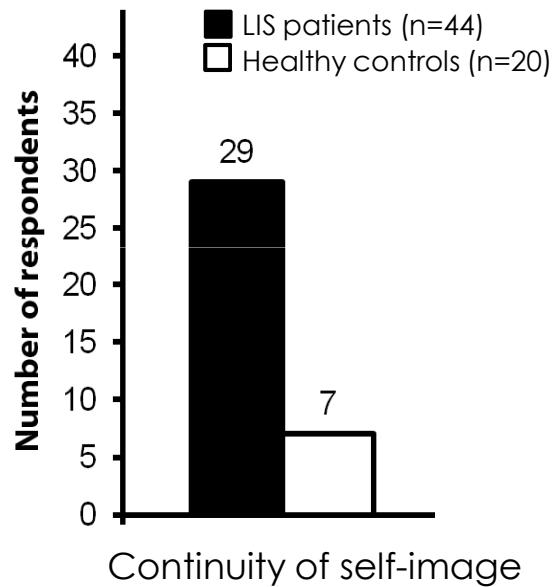
**Best
Period**

**Worst
period**





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



Nizzi et al, *Conscious & Cogn* 2012

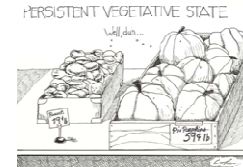


Nizzi et al., *NeuroEthics* 2018

« More dead than dead »

- ▶ 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!



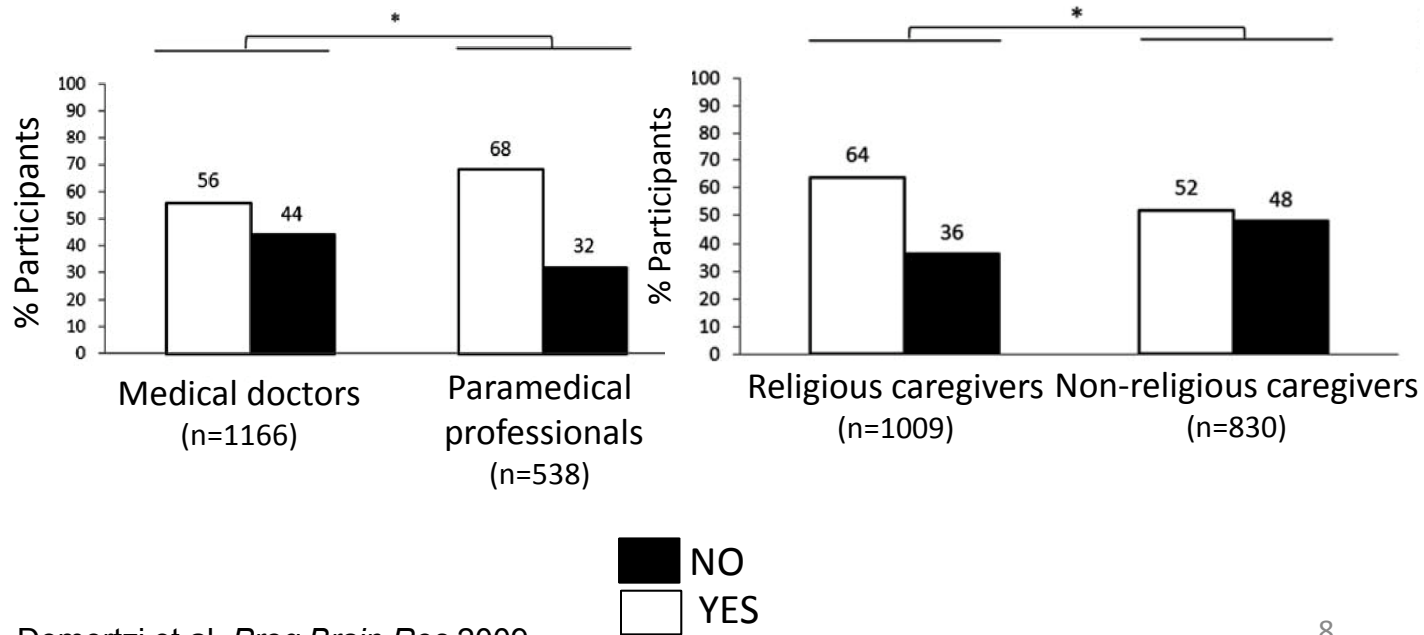
| **What does my relative feels** | My relative's future | Burden & Needs |



... about pain

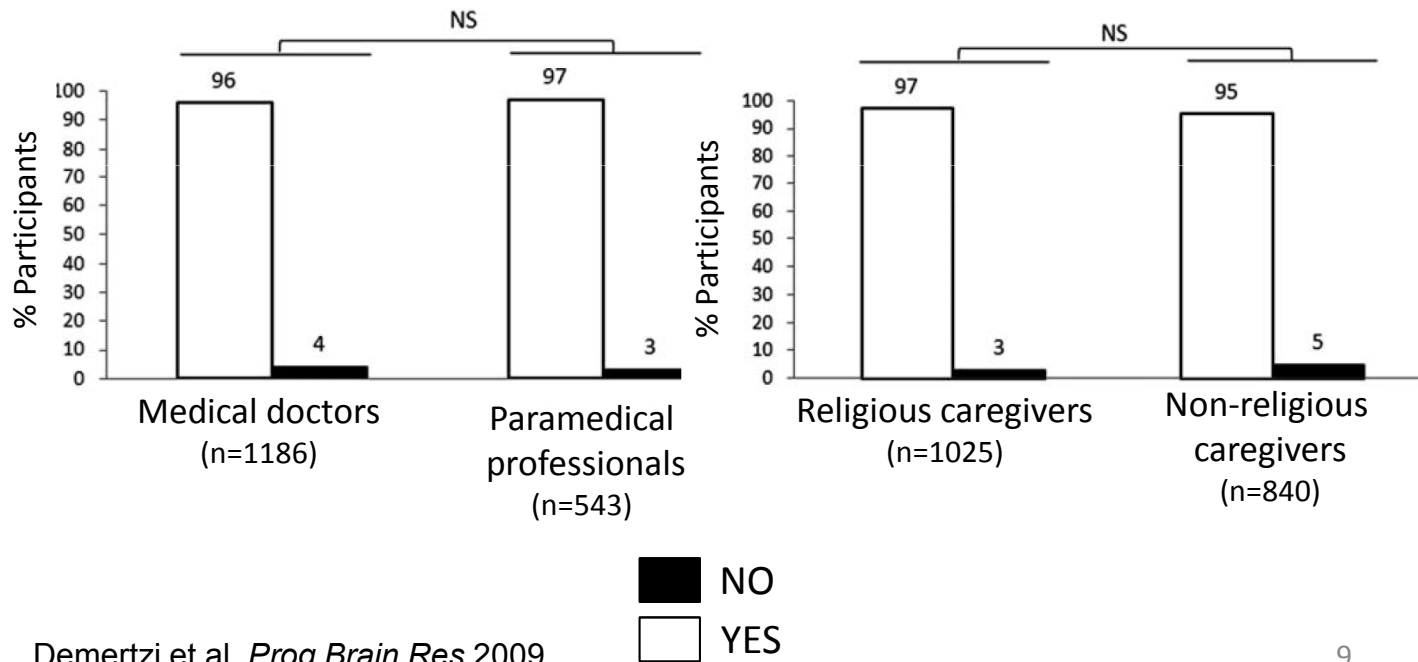
Caregivers are ambivalent about pain perception in UWS

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



Caregivers endorse pain perception in the MCS

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



New ways to communicate? Promising tools

Brain-Computer Interface (BCI)

"MOVE YOUR FOOT"



HEALTHY
CONTROL
SUBJECT

"MOVE YOUR HAND"



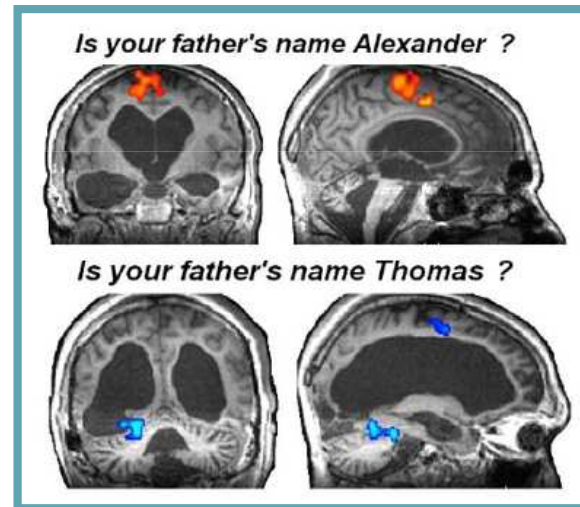
"VEGETATIVE"
UNRESPONSIVE
PATIENT



Cruse et al, *Lancet* 2012
See, too: Lesenfants et al, *J Neural Eng* 2014

Functional MRI (fMRI)

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



Monti et al., *New England J Med* 2010
Owen et al, *Science* 2006

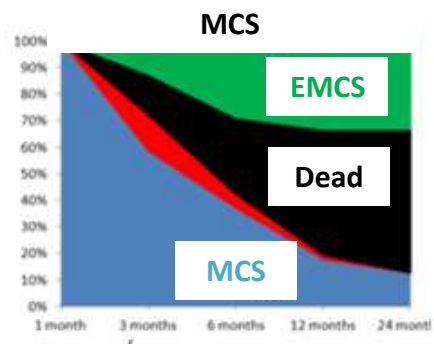
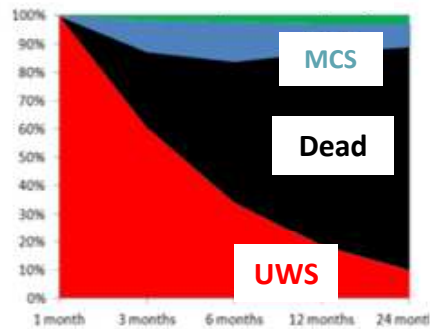
Communication and decision-making

- ▶ 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

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

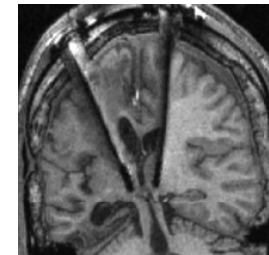
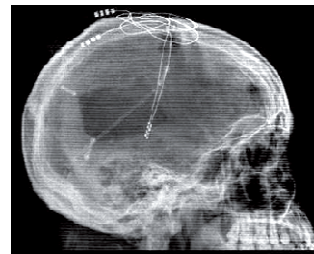
How can we envision the future?

TBI Prognostic
UWS

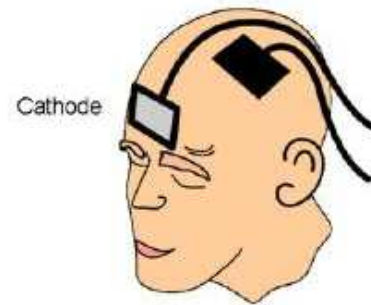


Cassol et al, *in preparation*

Treatment



Schiff et al, *Nature*, 2007



Thibaut et al, *Brain Inj* 2017

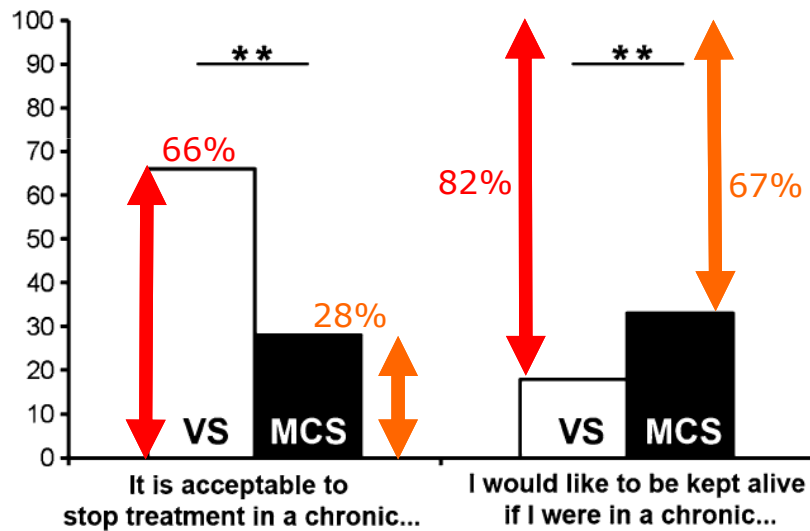
| On pain perception | **On medical management** | On needs and burden



... about end-of-life ?

End of life is supported more for the UWS

2,475 medical professionals



UWS/VS is worth than death

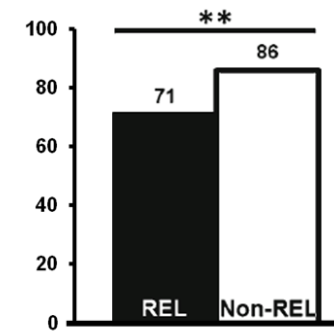
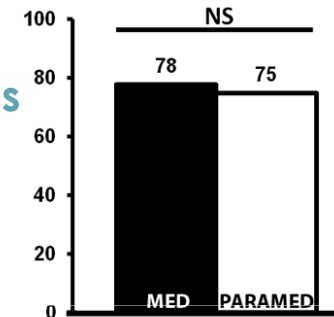
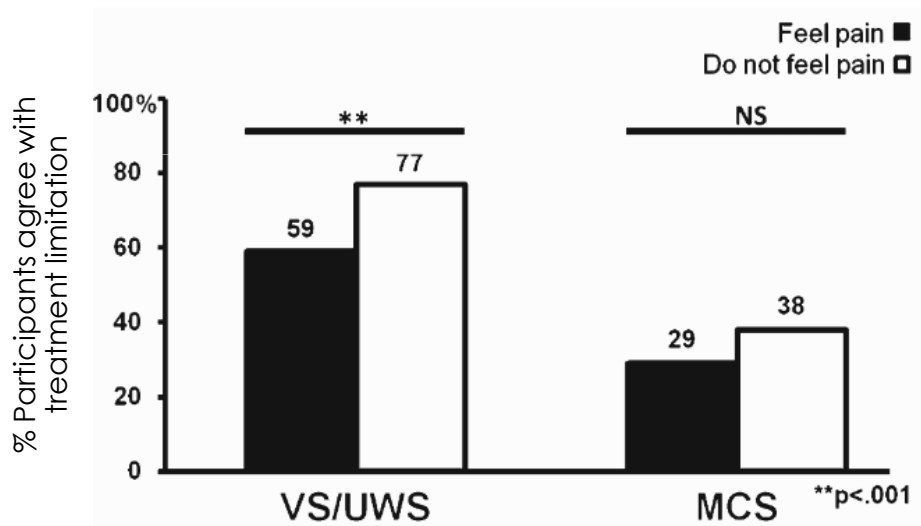
- Patients: 55%
- Families : 80%

MCS is worth than UWS/VS for

- Patients: 54%
- Families : 42%

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 of **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

Bernat, *Arch Neurol*, 2003; Bernat., *Neurol Clin*, 2004

Demertzi et al., *Désordres de la conscience: aspects éthiques. In Comas et états de conscience altérée*, 2011 ;¹⁶



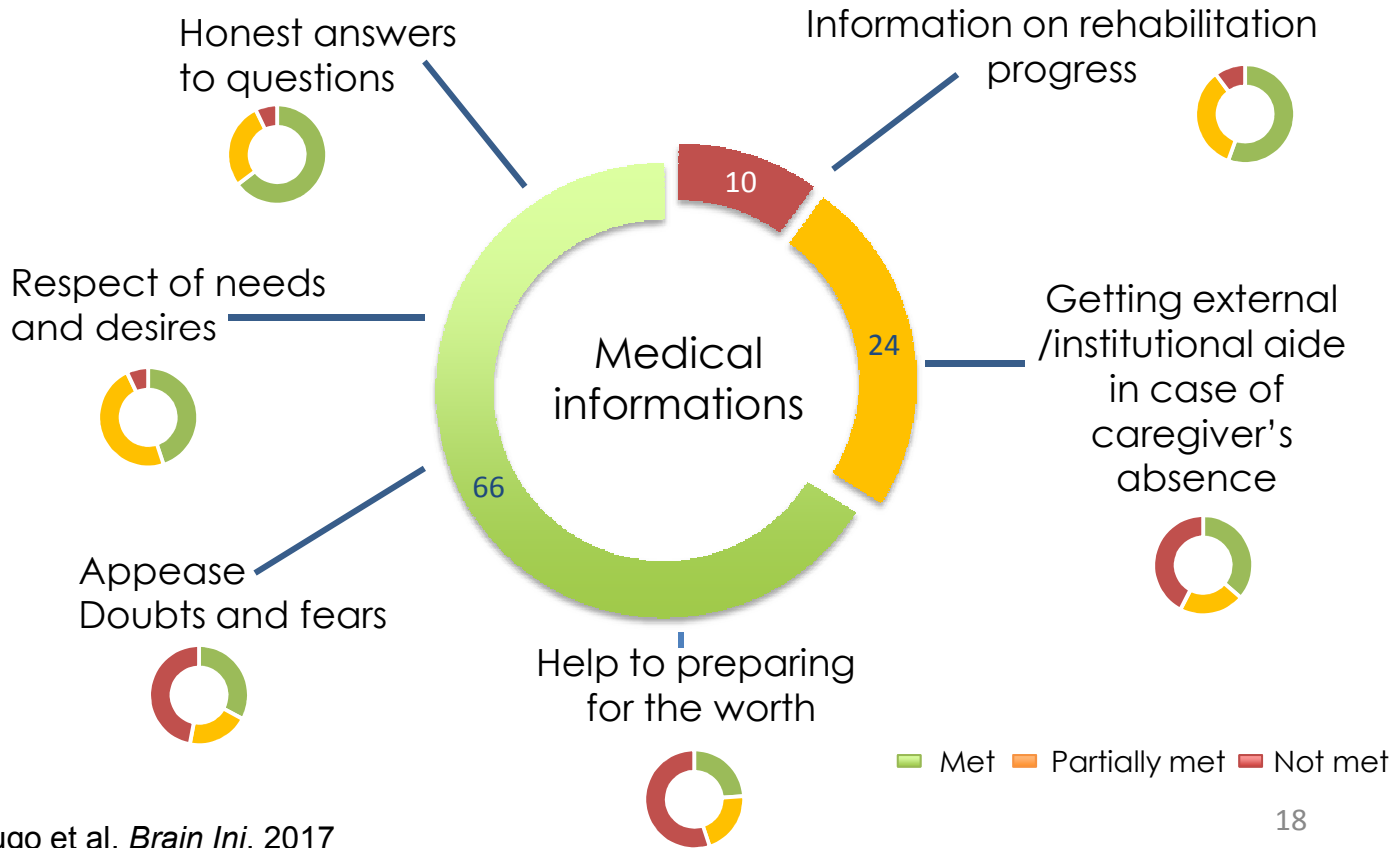
Family burden

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





Family needs in Locked-in Syndrome





What about DOC professional caregivers?

1/5 in burn-out

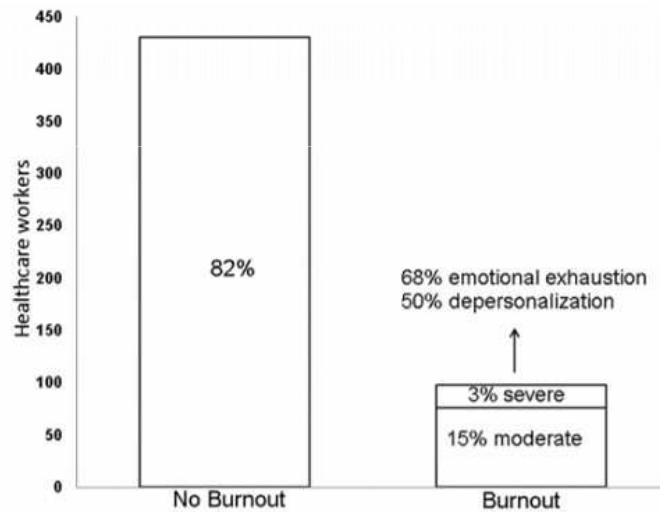


Table II. Percentage of burnout and its three sub-components among all participants.

| | Low | Moderate | High |
|----------------------|-----|----------|------|
| Burnout | 82% | 15% | 3% |
| Emotional exhaustion | 67% | 21% | 12% |
| Depersonalization | 64% | 27% | 9% |
| Accomplishment | 3% | 12% | 85% |

Table III. Percentage of healthcare workers presenting a burnout.

| Profession | Burnout |
|--------------------------------|---------|
| Physician | 8% |
| Nurse | 24% |
| Nursing assistant | 23% |
| Physio-/speech-/ergo-therapist | 8% |
| Psychologist/social worker | 10% |

Take Home Message

- 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**





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James S. McDonnell Foundation



Thanks for your attention !

...but mostly patients and their families!



For more informations: awolff@uliege.be