Neuroethical implications of clinician's attitudes toward the Locked-in Syndrome

Personhood and the Locked-In Syndrome
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CHERCHER, TROUVER, GUÉRIR, POUR VOUS & AVEC VOUS.

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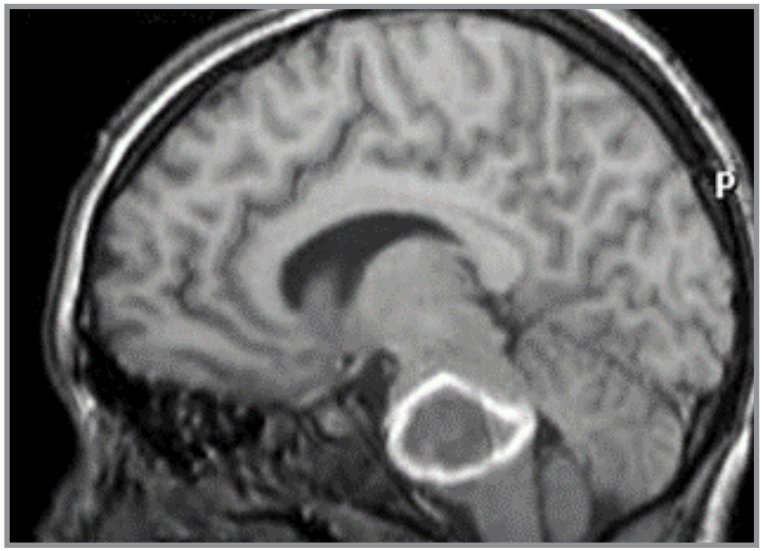
Locked-in syndrome (LIS)

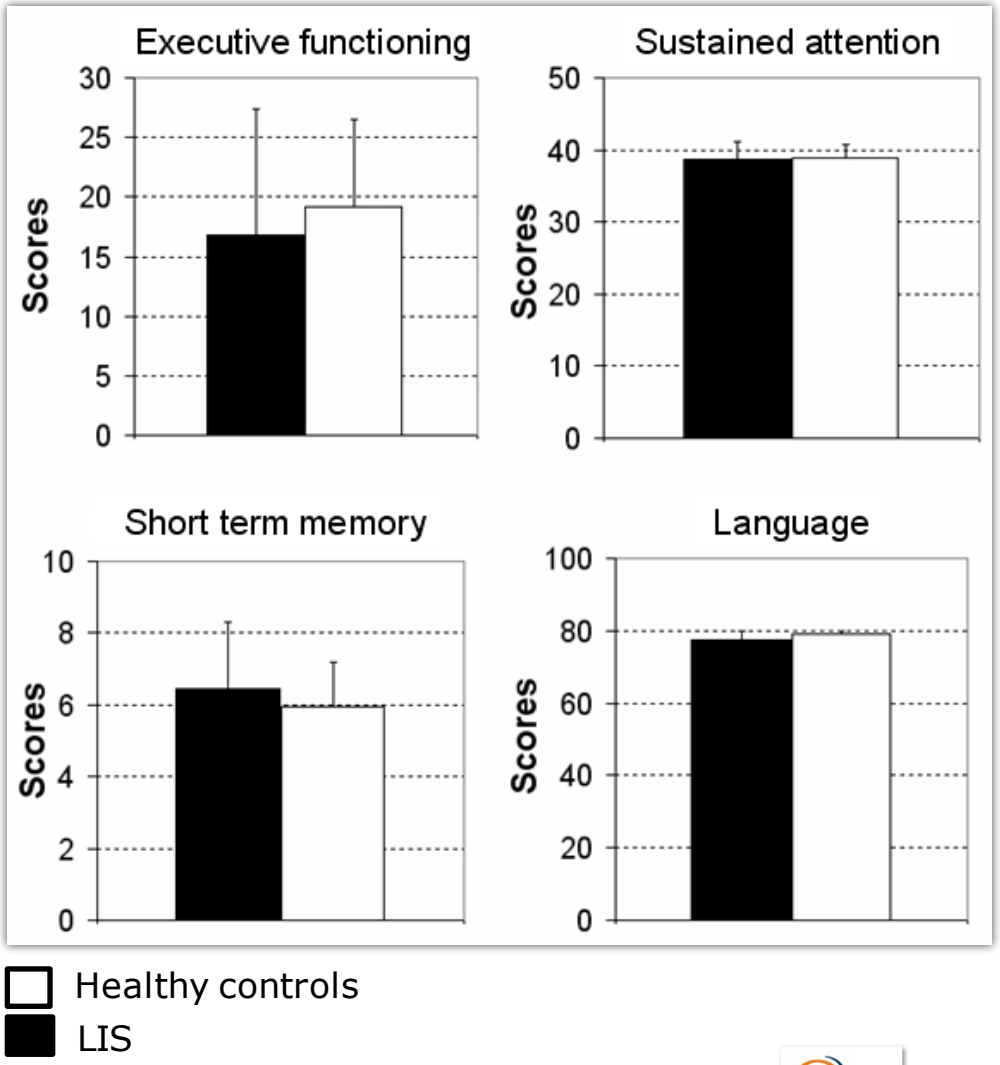
- Presence of sustained eye opening
- Aphonia or severe hypophonia
- Ocular mode of communication
- Quadriplegia or quadriparesis-Types:
  - Classical
  - Incomplete
  - Total
- Preserved cognitive abilities



Amercian Congress of Rehabilitation Medicine, 1995; Laureys et al, Prog in Brain Resc, 2005; Bauer et al, J Neurol, 1979

Cognitive function in LIS: behavior

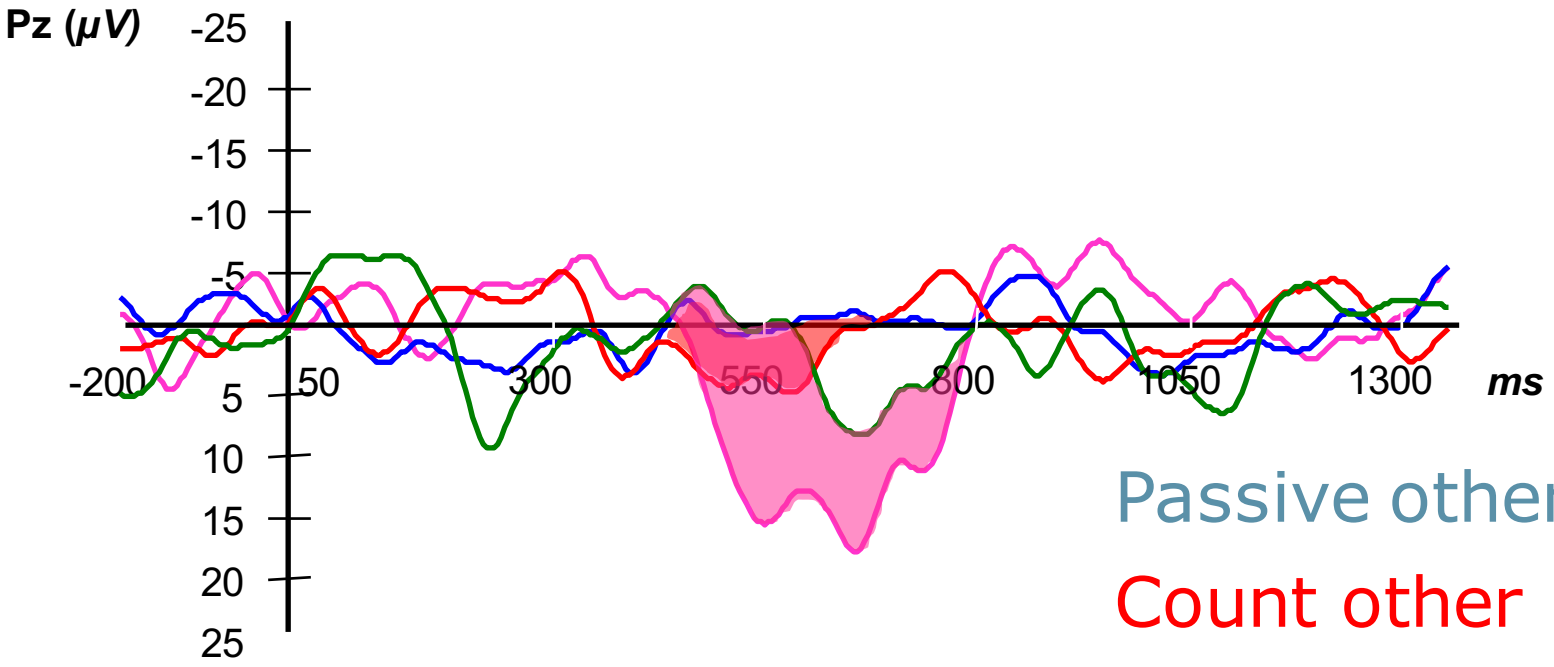
- N=10 (evaluated 1-6 yrs after insult)
- Neuropsychological tests (adapted)
- Pure brainstem lesions → intact cognitive levels
- Additional brain injuries→ associated cognitive deficits



Schnakers et al., J Neurol 2008

Cognitive function in LIS: brain

Total locked-in syndrome (n=1)



Passive other name

Count other name

Passive own name

Count own name

Schnakers et al., Neurocase 2009

The disability paradox

Albrecht & Devlieger, Socal Science and Medicine 1999

When partners or caregivers rate patients' quality of life, the scores are significantly lower than when patients do it for themselves

Lule D, Zickler C, Hacker S, Bruno M-A, Demertzi A, Pellas F, Laureys S, Kubler A. Progress in Brain Research 2009

Kubler A, Winter S, Ludolph AC, Hautzinger M, Birbaumer N. Neurorehabilitation and Neural Repair 2005

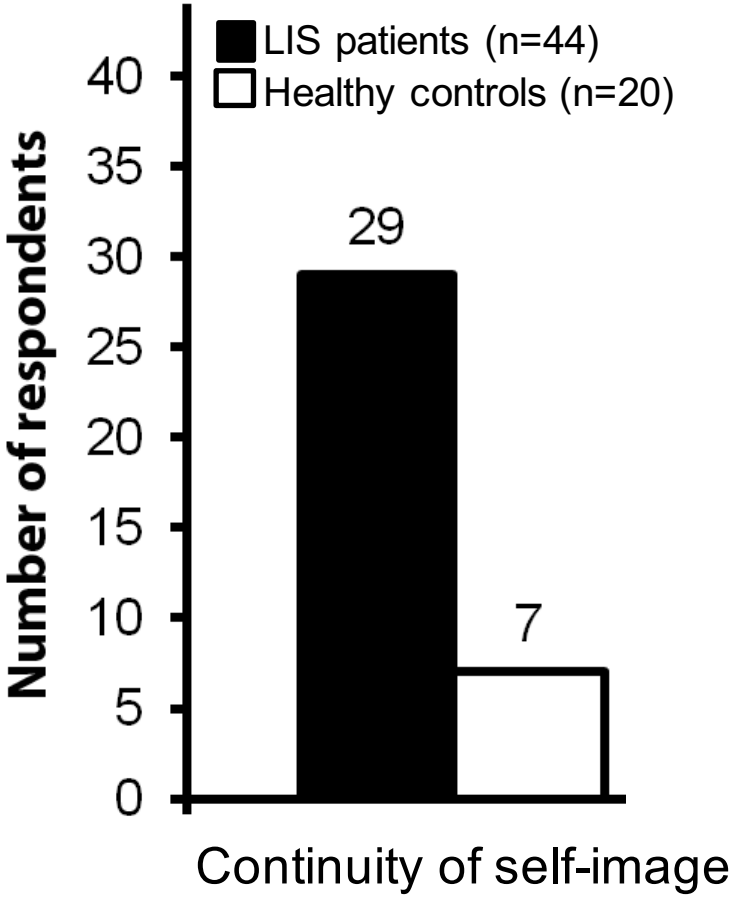
Doble JE, Haig AJ, Anderson C, Katz R. The Journal of Head Trauma Rehabilitation 2003

Katz RT, Haig AJ, Clark BB, DiPaola RJ. Archives of Physical Medicine and Rehabilitation 1992

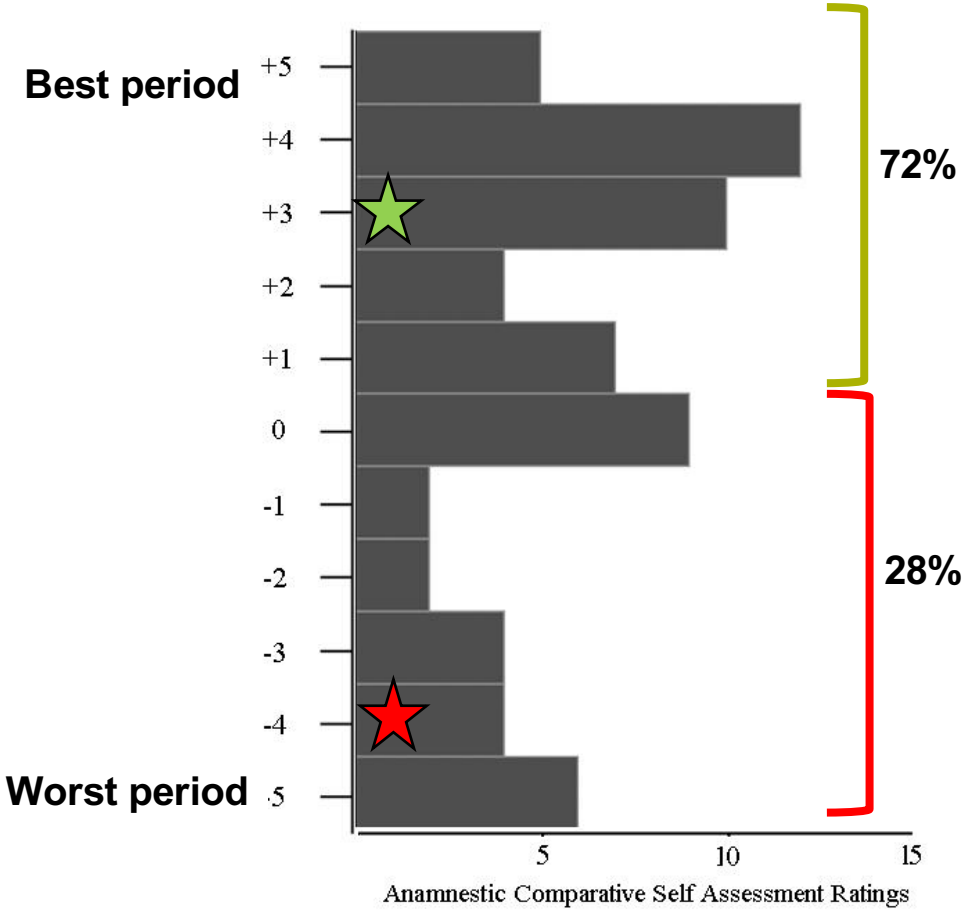
The disability paradox

Albrecht & Devlieger, Socal Science and Medicine 1999

Third *vs.* first-person perspective



Nizzi et al, Consciousness and Cognition 2012



Bruno et al, Br Med J Open 2011

Demertzi et al. 2013. "Quality of Life and End-of-Life Decisions after Brain Injury." In Reframing Disability and Quality of Life, Narelle Warren and Lenore Manderson (Eds), 95–110. Dordrecht: Springer.

The disability paradox

Albrecht & Devlieger, Socal Science and Medicine 1999

Third *vs.* first-person perspective

n=65 LIS patients
time in LIS: 1-28 yrs

Table 3 Significant associations between happiness status and variables identified by the univariate analyses (marked by an asterisk in table 2)

	Odds ratio	SE	Z score	p>|z|	95% CI
Duration in LIS*	1.5	0.2	2.71	0.007	1.1 to 2.0
Speech production	20.47	24.87	2.48	0.013	1.89 to 221.45
Anxiety	0.19	0.15	−2.14	0.032	0.04 to 0.87

*Odds ratio per year in LIS.
LIS, locked-in syndrome.

58% : no resuscitatation

7%: euthanasia wishes

Misdiagnosis of LIS

Person who made the diagnosis	Number of patients (n=84) (% of total)
Medical doctor	52 (62%)
Family member	28 (33%)
Other	4 (5%)

- **Misdiagnosis explain by :**
  - Rarity of LIS
  - Recognize signs of consciousness
  - Fluctuation of vigilance
  - Cognitive/sensory deficits

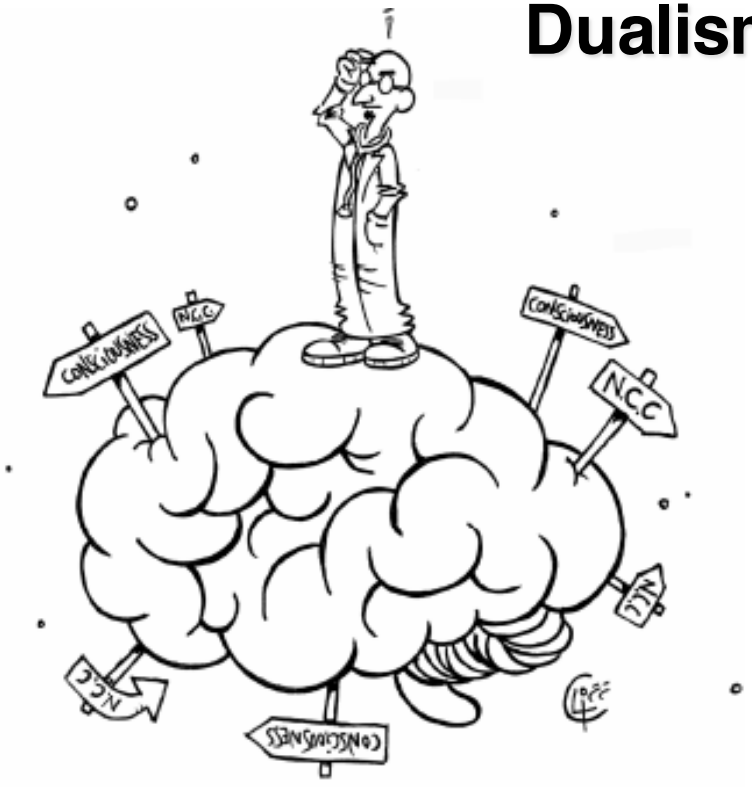
Bruno et al., Pediatric Neurology 2009
Laureys et al., Prog Brain Res 2005

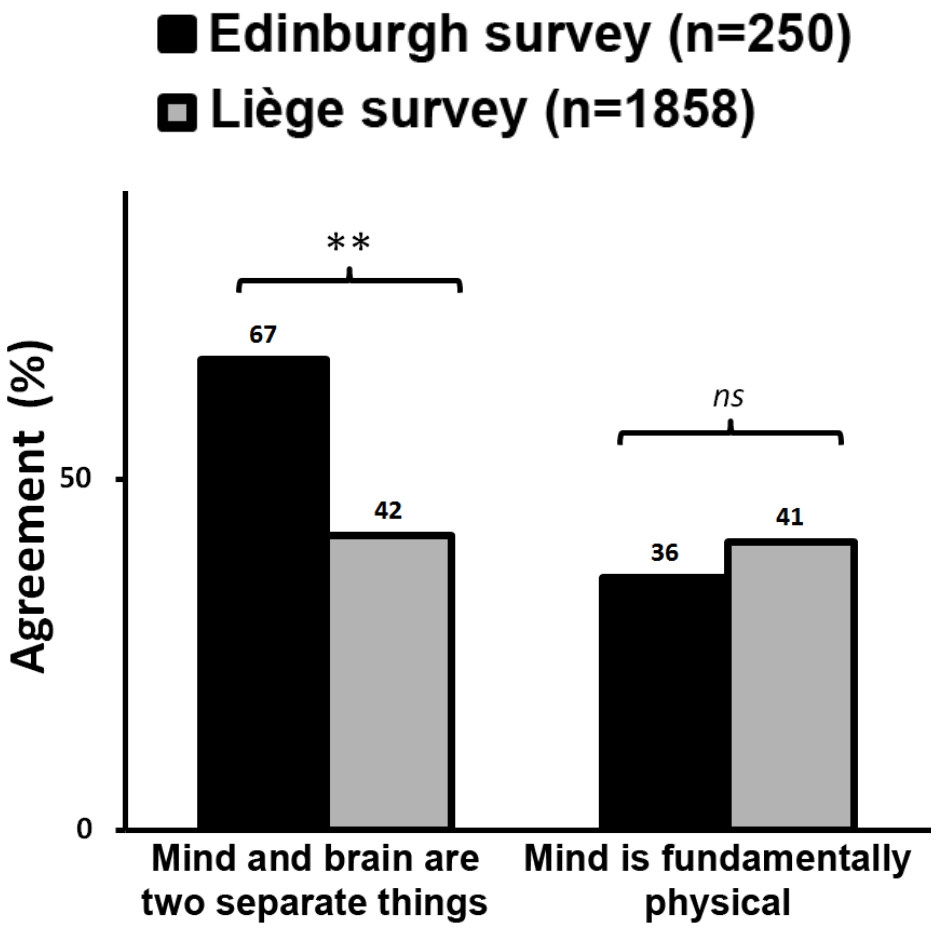
Consciousness

Functionalism

Materialism

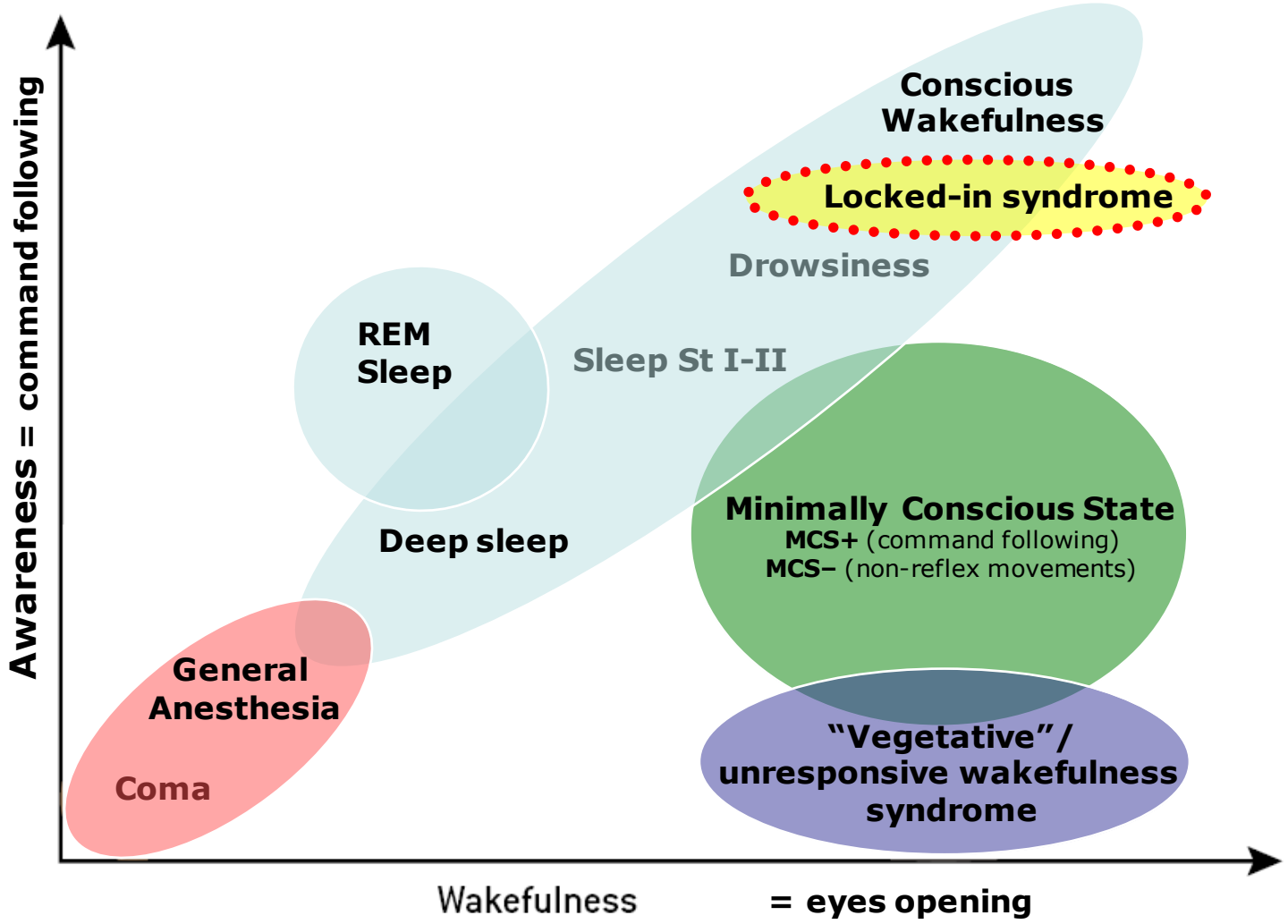
Dualism





Dualism Persists in the Science of Mind

LIS within the spectrum of consciousness



Demertzi et al, Encyclopedia of Consciousness 2009; Demertzi et al, Expert Review in Neurotherapeutics 2008
Laureys, Trends in Cognitive Sciences 2005

Attitudes towards LIS: survey

Item	Response	Frequency (%)
Do you think that patients in a LIS can feel pain?	Yes	2995 (90%)
	No	292 (9%)
	Missing data	45 (1%)
Do you think that treatment can be stopped in patients in chronic LIS?	Yes	789 (24%)
	No	2473 (74%)
	Missing data	70 (2%)
Would you like to be kept alive if you were in chronic LIS?	Yes	1412 (42%)
	No	1825 (55%)
	Missing data	95 (3%)
Being in a chronic (i.e. > 1 year) in LIS is worse than being in a VS or in a MCS for the family?	Yes	1333 (40%)
	No	1875 (56%)
	Missing data	124 (4%)
Being in a chronic (i.e. > 1 year) in LIS is worse than being in a VS or in a MCS for the patient?	Yes	1963 (59%)
	No	1258 (38%)
	Missing data	111 (3%)

Conferences and meetings (n= 59) in Europe (September 2007 -October 2009)

n=3332 respondents, 33 European countries

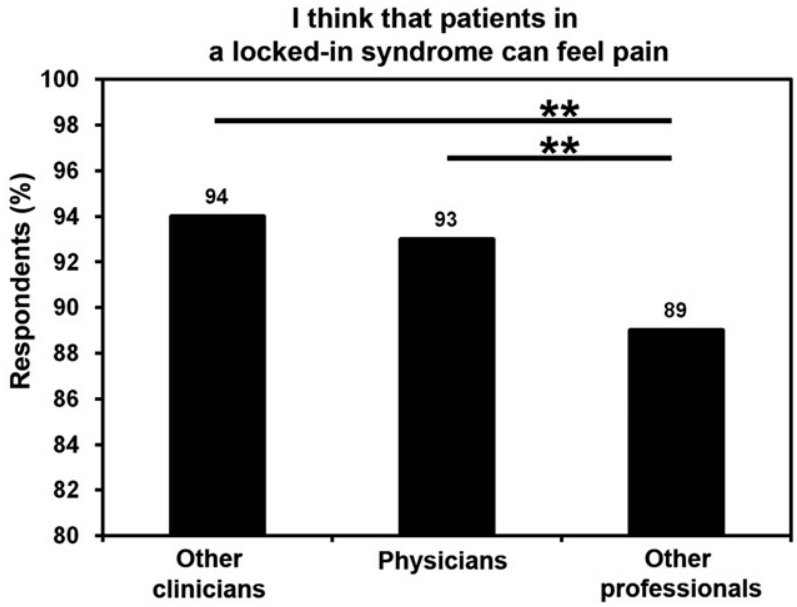
- 33% Physicians 33%
- 18% Other clinicians
- 49% Other professionals

Attitudes towards LIS: pain

Item	Response	Frequency (%)
Do you think that patients in a LIS can feel pain?	Yes	2995 (90%)
	No	292 (9%)
	Missing data	45 (1%)

→ 60% Students and pupils
28% physicians
12% and other clinicians

Predictor variable	I think patients in a LIS feel pain (Odds ratio, 95% CI)
Age[1]	0.99 (0.98–1.00)
Women	1.02 (0.79–1.33)
North Europe	1
Central Europe	0.67 (0.46–0.99)*
South Europe	0.73 (0.49–1.10)
Physicians	1
Other clinicians	1.08 (0.70–1.66)
Other professionals	0.58 (0.42–0.81)**
Religious	1.10 (0.85–1.41)

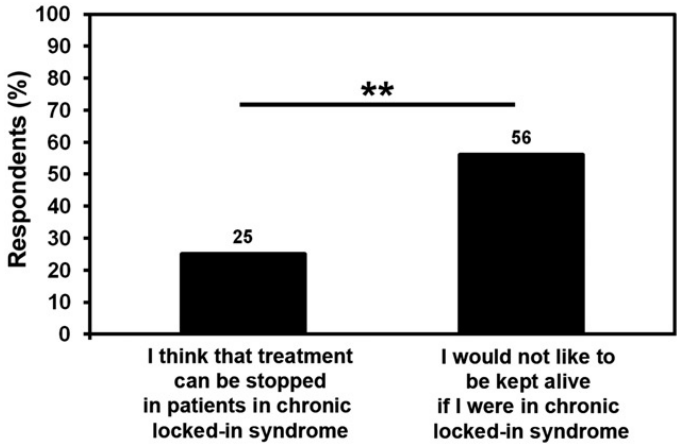


I think that patients in MCS feel pain: 96%
I think that patients in VS/UWS feel pain: 59% VS/UWS (n=2059)

Demertzi et al, Progress in Brain Research 2009

Attitudes towards LIS: end of life

Item	Response	Frequency (%)
Do you think that treatment can be stopped in patients in chronic LIS?	Yes	789 (24%)
	No	2473 (74%)
	Missing data	70 (2%)
Would you like to be kept alive if you were in chronic LIS?	Yes	1412 (42%)
	No	1825 (55%)
	Missing data	95 (3%)



Predictor variable	I think that treatment can be stopped in patients in chronic LIS (Odds ratio, 95% CI)	I would like to be kept alive if I were in chronic LIS (Odds ratio, 95% CI)
Age[1]	1.00 (0.99–1.00)	1.00 (0.99–1.00)
Women	0.96 (0.80–1.15)	0.85 (0.72–0.99)*
North Europe	1	1
Central Europe	1.12 (0.89–1.41)	0.72 (0.59–0.89)*
South Europe	0.65 (0.50–0.84)**	0.72 (0.58–0.90)*
Physicians	1	1
Other clinicians	1.03 (0.78–1.34)	0.79 (0.63–0.99)*
Other professionals	1.30 (1.03–1.63)*	1.13 (0.93–1.36)
Religious	0.50 (0.42–0.60)**	1.69 (1.46–1.96)**

(n=2059)

Attitudes towards LIS and Disorders of C

Item	Response	Frequency (%)	
Being in a chronic (i.e. > 1 year) in LIS is worse than being in a VS or in a MCS for the family?	Yes	1333 (40%)	**
	No	1875 (56%)	
	Missing data	124 (4%)	
Being in a chronic (i.e. > 1 year) in LIS is worse than being in a VS or in a MCS for the patient?	Yes	1963 (59%)	
	No	1258 (38%)	
	Missing data	111 (3%)	

- MCS worse than VS for the patient: 54%
- MCS worse than VS for their families: 42%

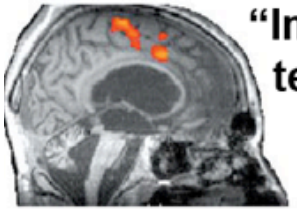
- VS worse than death for the patient: 55%
- VS worse than death for their families: 80%

→ Consciousness matters

Demertzi et al, Journal of Neurology 2011

Detecting awareness

Active paradigms

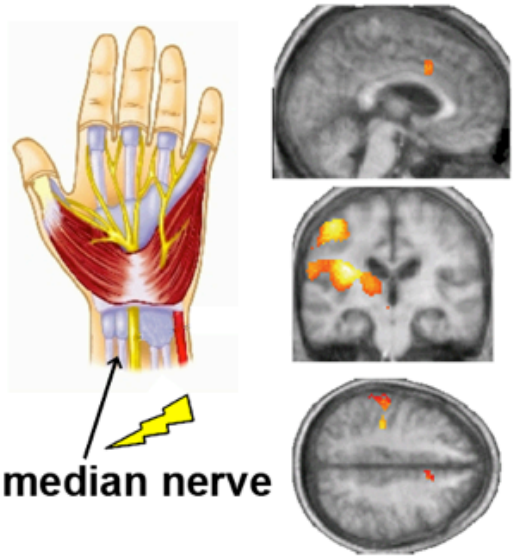


"Imagine playing tennis"

"Imagine visiting the rooms of your house"

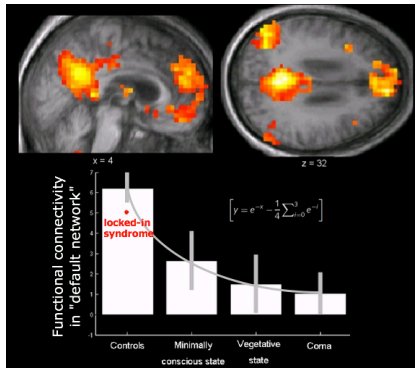
Owen et al, Science 2006
Monti & Vanhaudenhuyse et al, NEJM 2010

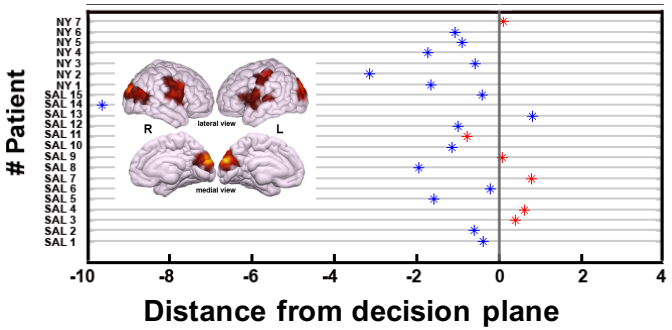
Passive paradigms



Boly et al, Lancet Neurol 2008

Resting state





Vanhaudenhuyse & Noirhomme, Brain 2010
Demertzi & Antonopoulos, Brain 2015

Heine, Di Perri, Soddu, Laureys, Demertzi
In: *Clinical Neurophysiology in Disorders of Consciousness,* Springer-Verlag 2015

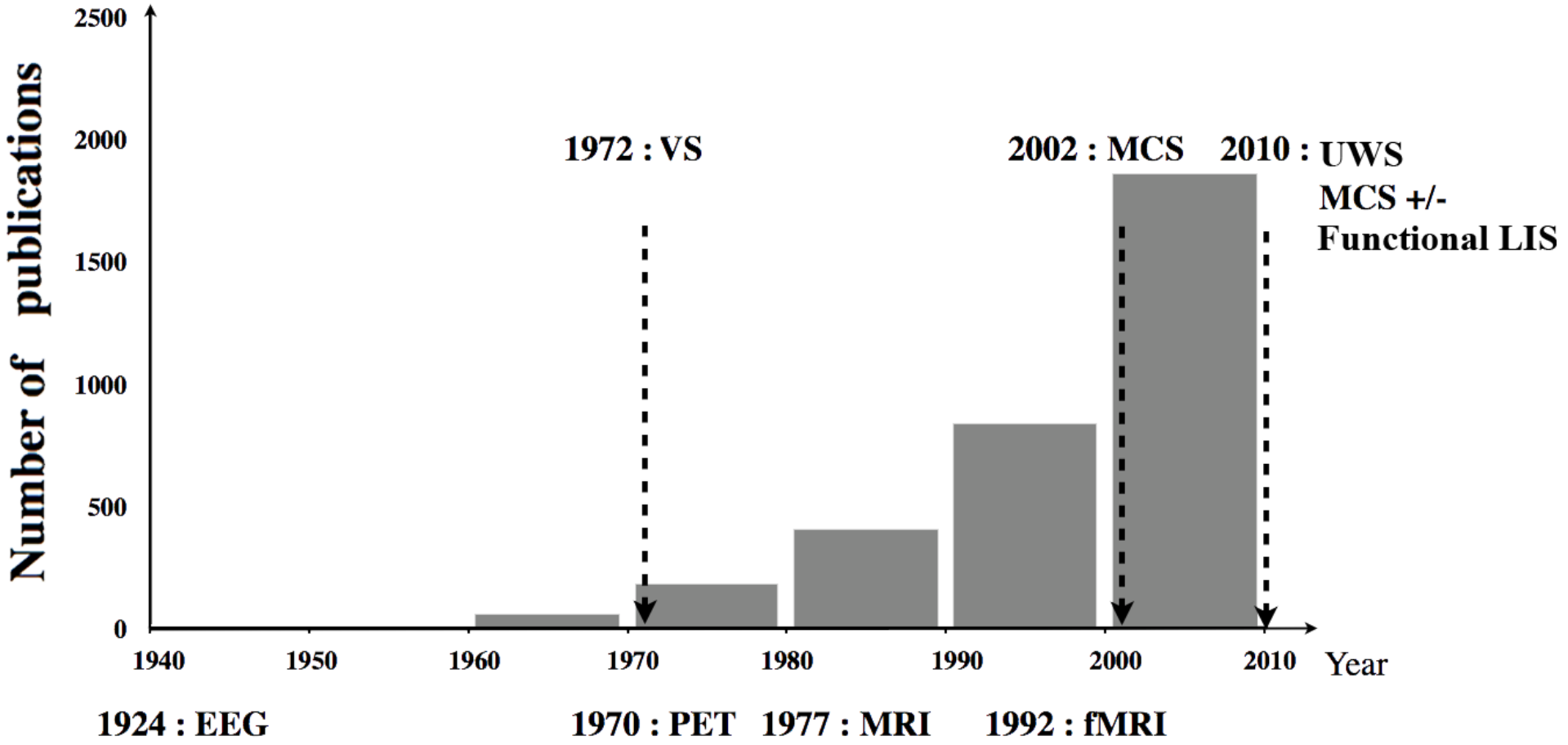
Demertzi & Laureys, In: *I know what you are thinking: brain imaging and mental privacy*, Oxford University Press 2012

The ethical relevance of technology-based assessment

Results of Tests	Beneficial Effects	Harmful Effects
- brain activity than neurological examination	Relatives: decisions to limit life-sustaining treatment	Relatives: may lose hope, purpose, and meaning in life
+ brain activity than neurological examination	Clinical management: may be intensified by the chance of further recovery	Relatives: false hopes
Same as neurological examination	Clinicians & relatives: may be affirmed in their decision about the level of treatment	Clinicians & relatives: may be disappointed & treatment cost/effectiveness may be poor

Jox, Bernat, Laureys, Racine, Lancet Neurology 2012

New knowledge, new nosology



Gantner, Bodard, Laureys & Demertzi, Fut Neurol 2013
Bruno & Vanhaudenhuyse et al, J Neurology 2011

Conclusions

Clinicians ascribe mind (pain) in LIS

Support for end of life: the respondents could also have recognized the patients' right to autonomy and, hence, supported treatment limitation

The moral significance of Consciousness

- ontological understanding: consciousness =personhood = moral agency
- relational or contextual understanding: patients have value for others
- but, the presence of consciousness alone does not always work in favour of patients' best interest because it jeopardizes good quality of life

Legal challenges: responses to critical questions with NI

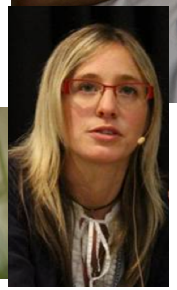
Cognitive neuroscience is about brain/mind reading: to what degree do we neuroscientists have the right to interfere with a patient's intimacy, such as cognitive contents, in the absence of their consent?

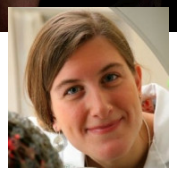
Thank you!

Coma Science Group & PICNIC Lab

The deparments of Neurology and Radiology in Liège and Paris

…and mostly patients and their families!





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