Questions éthiques dans la prise en charge des patients sévèrement cérébrolésés

Journée conférence

Troubles de la conscience: rencontre entre recherche, pratique clinique et enjeux éthiques

8 juin 2018

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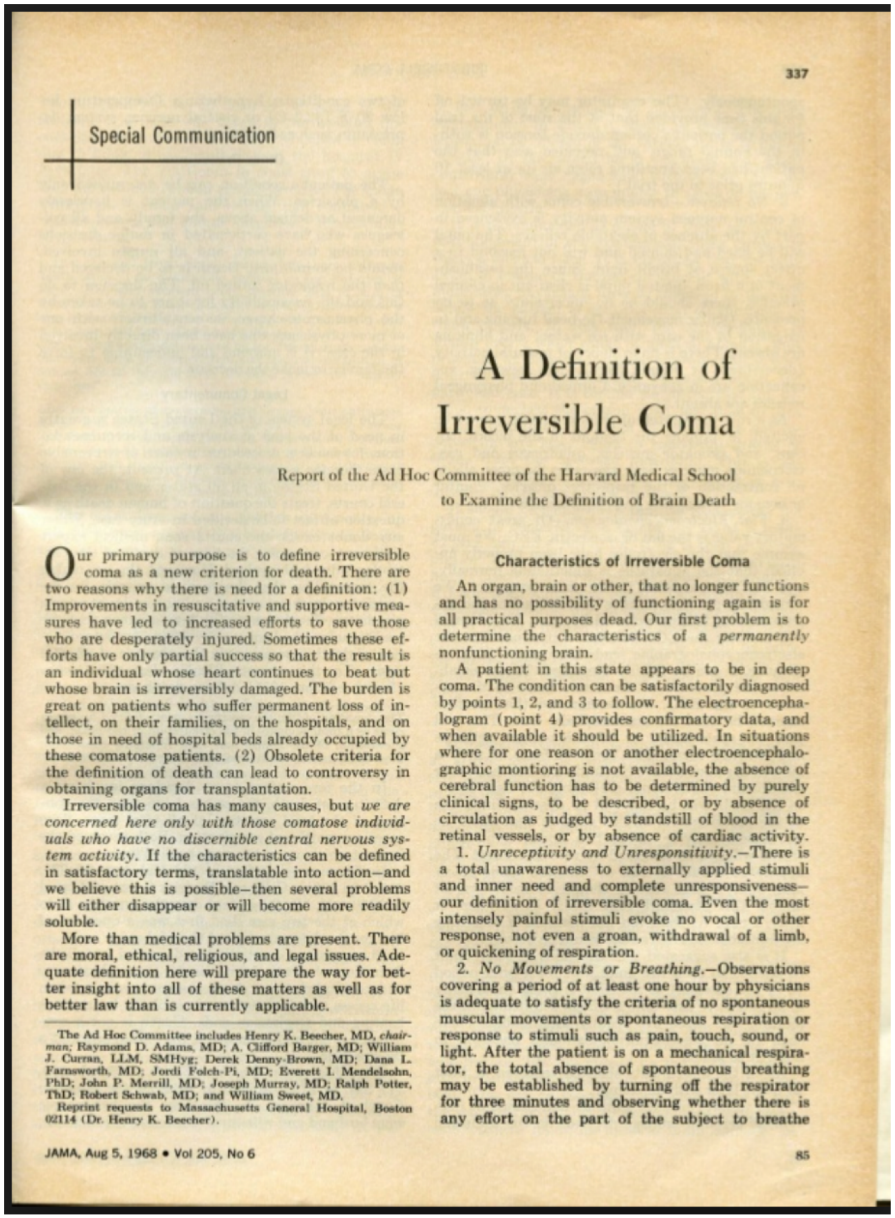
University & University Hospital of Liège
Begique

Il était une fois…

la ventilation mécanique

Bjørn Ibsen (Copenhagen)

Bioéthique



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Special Communication

A Definition of Irreversible Coma

Report of the Ad Hoc Committee of the Harvard Medical School to Examine the Definition of Brain Death

Our primary purpose is to define irreversible coma as a new criterion for death. There are two reasons why there is need for a definition: (1) Improvements in resuscitative and supportive measures have led to increased efforts to save those who are desperately injured. Sometimes these efforts have only partial success so that the result is an individual whose heart continues to beat but whose brain is irreversibly damaged. The burden is great on patients who suffer permanent loss of intellect, on their families, on the hospitals, and on those in need of hospital beds already occupied by these comatose patients. (2) Obsolete criteria for the definition of death can lead to controversy in obtaining organs for transplantation.

Irreversible coma has many causes, but *we are concerned here only with those comatose individuals who have no discernible central nervous system activity*. If the characteristics can be defined in satisfactory terms, translatable into action—and we believe this is possible—then several problems will either disappear or will become more readily soluble.

More than medical problems are present. There are moral, ethical, religious, and legal issues. Adequate definition here will prepare the way for better insight into all of these matters as well as for better law than is currently applicable.

The Ad Hoc Committee includes Henry K. Beecher, MD, *chairman;* Raymond D. Adams, MD; A. Clifford Barger, MD; William J. Curran, LLM, SMHyg; Derek Denny-Brown, MD; Dana L. Farnsworth, MD; Jordi Folch-Pi, MD; Everett I. Mendelsohn, PhD; John P. Merrill, MD; Joseph Murray, MD; Ralph Potter, ThD; Robert Schwab, MD; and William Sweet, MD.

Reprint requests to Massachusetts General Hospital, Boston 02114 (Dr. Henry K. Beecher).

Characteristics of Irreversible Coma

An organ, brain or other, that no longer functions and has no possibility of functioning again is for all practical purposes dead. Our first problem is to determine the characteristics of a *permanently* nonfunctioning brain.

A patient in this state appears to be in deep coma. The condition can be satisfactorily diagnosed by points 1, 2, and 3 to follow. The electroencephalogram (point 4) provides confirmatory data, and when available it should be utilized. In situations where for one reason or another electroencephalographic montioring is not available, the absence of cerebral function has to be determined by purely clinical signs, to be described, or by absence of circulation as judged by standstill of blood in the retinal vessels, or by absence of cardiac activity.

1. *Unreceptivity and Unresponsitivity.*—There is a total unawareness to externally applied stimuli and inner need and complete unresponsiveness—our definition of irreversible coma. Even the most intensely painful stimuli evoke no vocal or other response, not even a groan, withdrawal of a limb, or quickening of respiration.

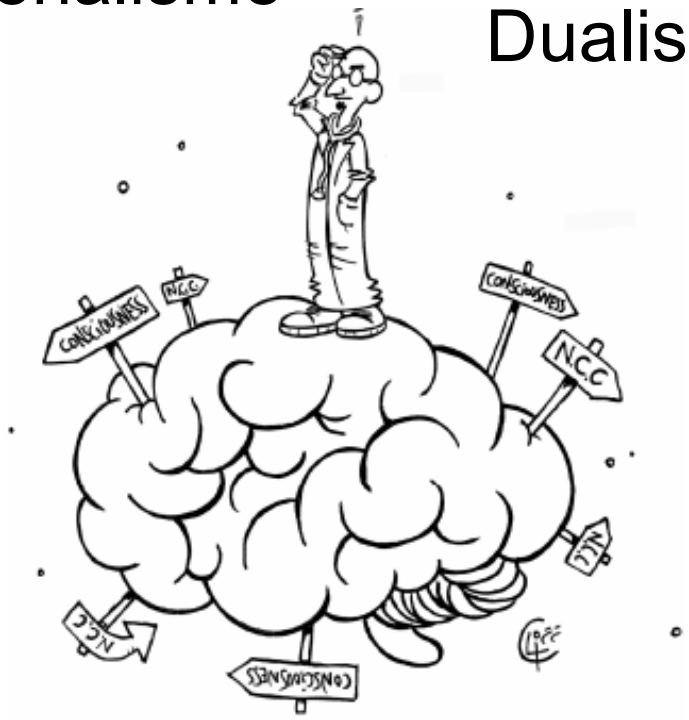
2. *No Movements or Breathing.*—Observations covering a period of at least one hour by physicians is adequate to satisfy the criteria of no spontaneous muscular movements or spontaneous respiration or response to stimuli such as pain, touch, sound, or light. After the patient is on a mechanical respirator, the total absence of spontaneous breathing may be established by turning off the respirator for three minutes and observing whether there is any effort on the part of the subject to breathe

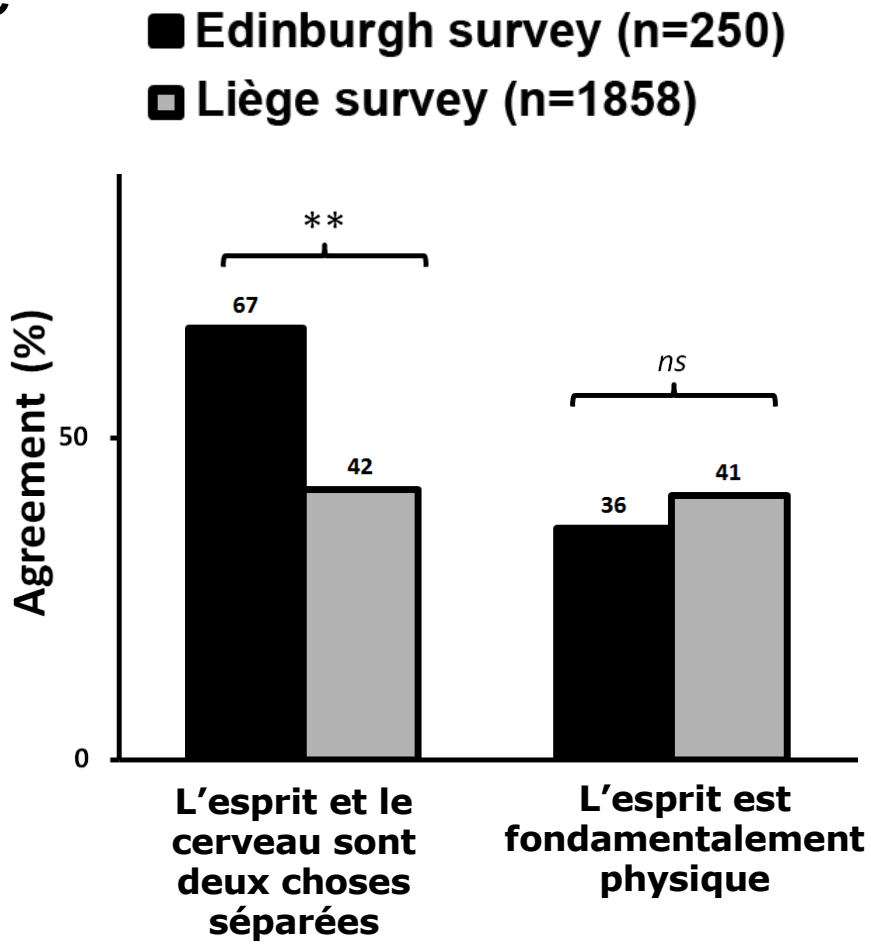
Quelle conscience?

Fonctionnalisme

Matérialisme

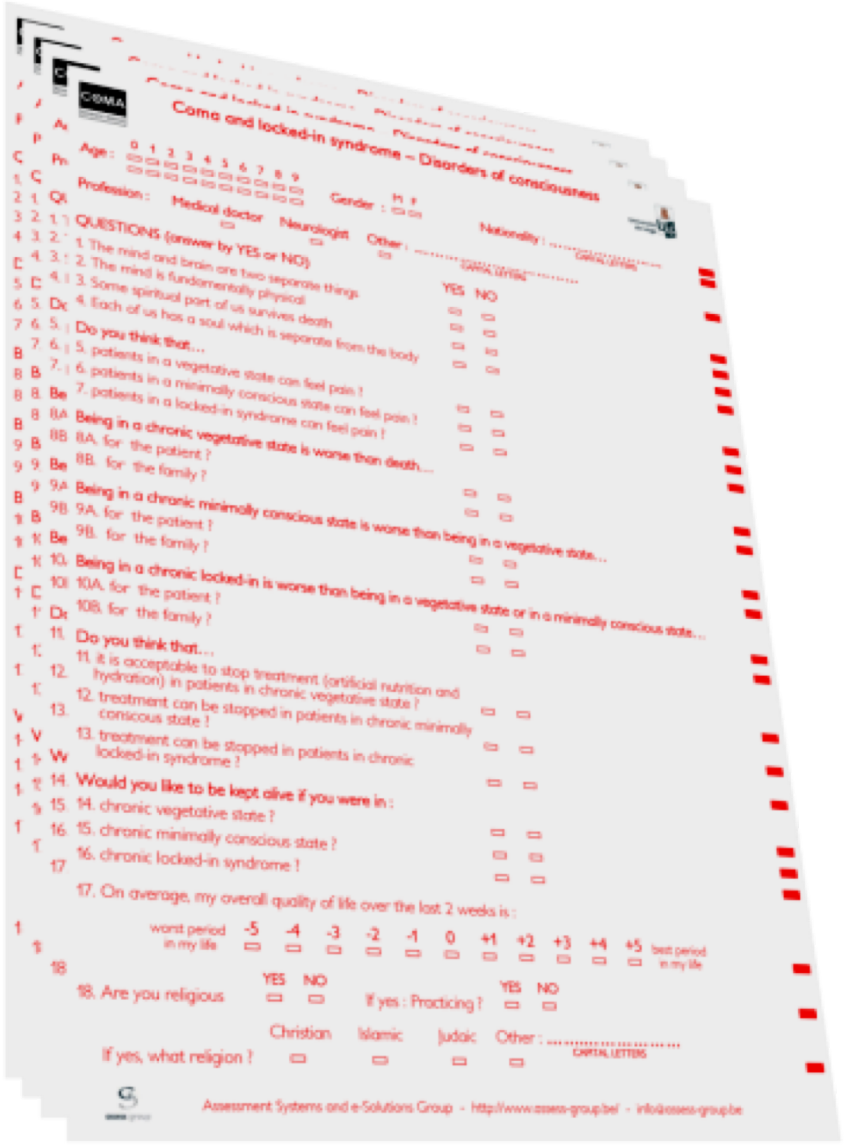
Dualisme





Demertzi et al, *Annals of the New York Academy of Sciences* 2009

Que pensez-vous …


Coma and locked-in syndrome – Disorders of consciousness

Age : 0 1 2 3 4 5 6 7 8 9 Gender : m f

Profession : Medical doctor Neurologist Other : ..... Nationality : .....

QUESTIONS (answer by YES or NO) YES NO

1. The mind and brain are two separate things
2. The mind is fundamentally physical
3. Some spiritual part of us survives death
4. Each of us has a soul which is separate from the body

Do you think that...

5. patients in a vegetative state can feel pain ?
6. patients in a minimally conscious state can feel pain ?
7. patients in a locked-in syndrome can feel pain ?

8A Being in a chronic vegetative state is worse than death...
8A. for the patient ?
8B. for the family ?

9A Being in a chronic minimally conscious state is worse than being in a vegetative state...
9A. for the patient ?
9B. for the family ?

10. Being in a chronic locked-in is worse than being in a vegetative state or in a minimally conscious state...
10A. for the patient ?
10B. for the family ?

11. Do you think that...
11. it is acceptable to stop treatment (artificial nutrition and hydration) in patients in chronic vegetative state ?
12. treatment can be stopped in patients in chronic minimally conscious state ?
13. treatment can be stopped in patients in chronic locked-in syndrome ?

14. Would you like to be kept alive if you were in :
14. chronic vegetative state ?
15. chronic minimally conscious state ?
16. chronic locked-in syndrome ?

17. On average, my overall quality of life over the last 2 weeks is :

worst period in my life -5 -4 -3 -2 -1 0 +1 +2 +3 +4 +5 best period in my life

18. Are you religious YES NO If yes : Practicing ? YES NO

If yes, what religion ? Christian Islamic Judaic Other : ..... CAPITAL LETTERS

Assessment Systems and e-Solutions Group - http://www.assess-group.be/ - info@assess-group.be

… par rapport à:

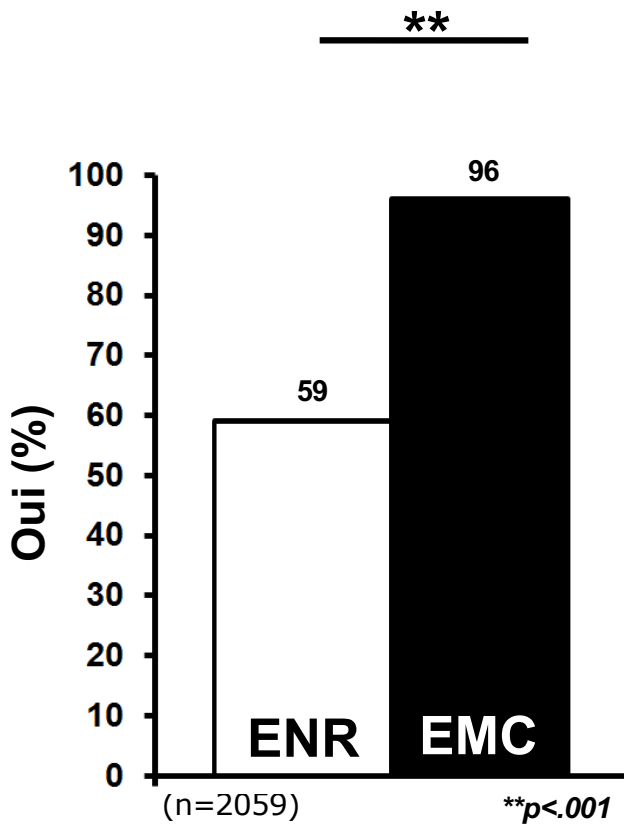
- la douleur
- la fin de vie

La douleur

«La douleur est une expérience sensorielle et émotionnelle désagréable, associée à un dommage tissulaire présent au potentiel, ou décrite en terme d'un tel dommage »
(IASP 1994)

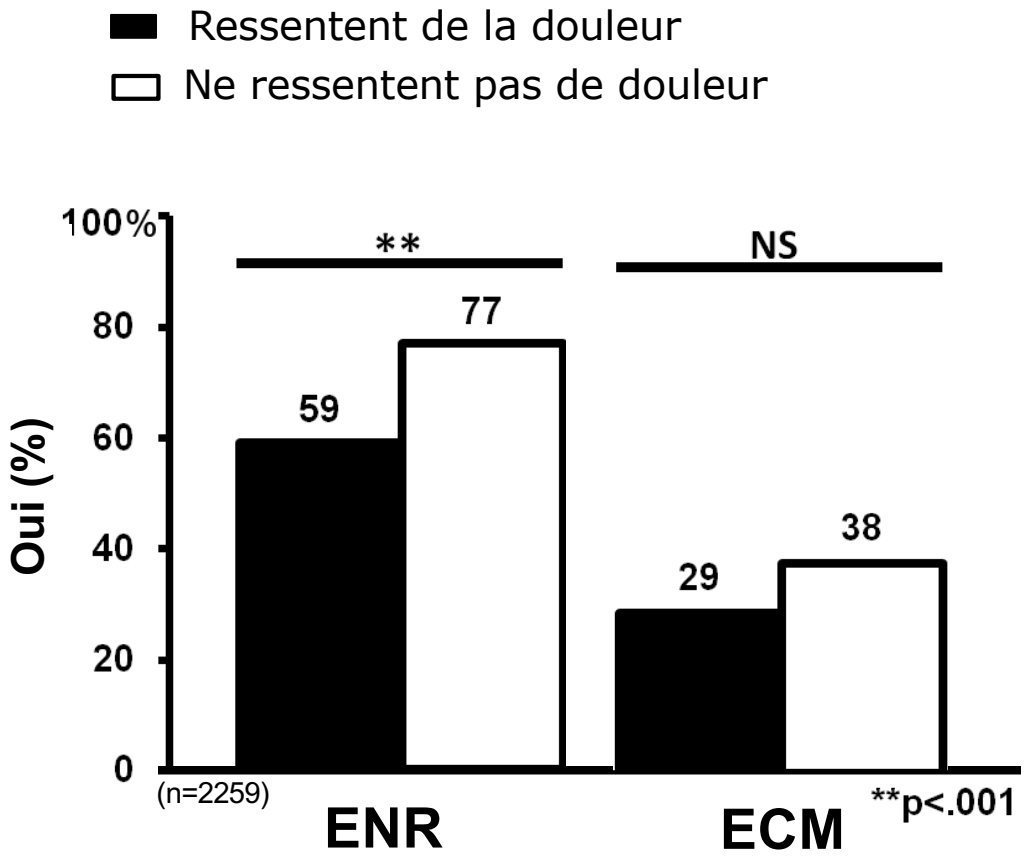
Opinions sur la douleur

Vous pensez que les patients …. peuvent ressentir de la douleur?



Demertzi et al, Progress in Brain Research 2009

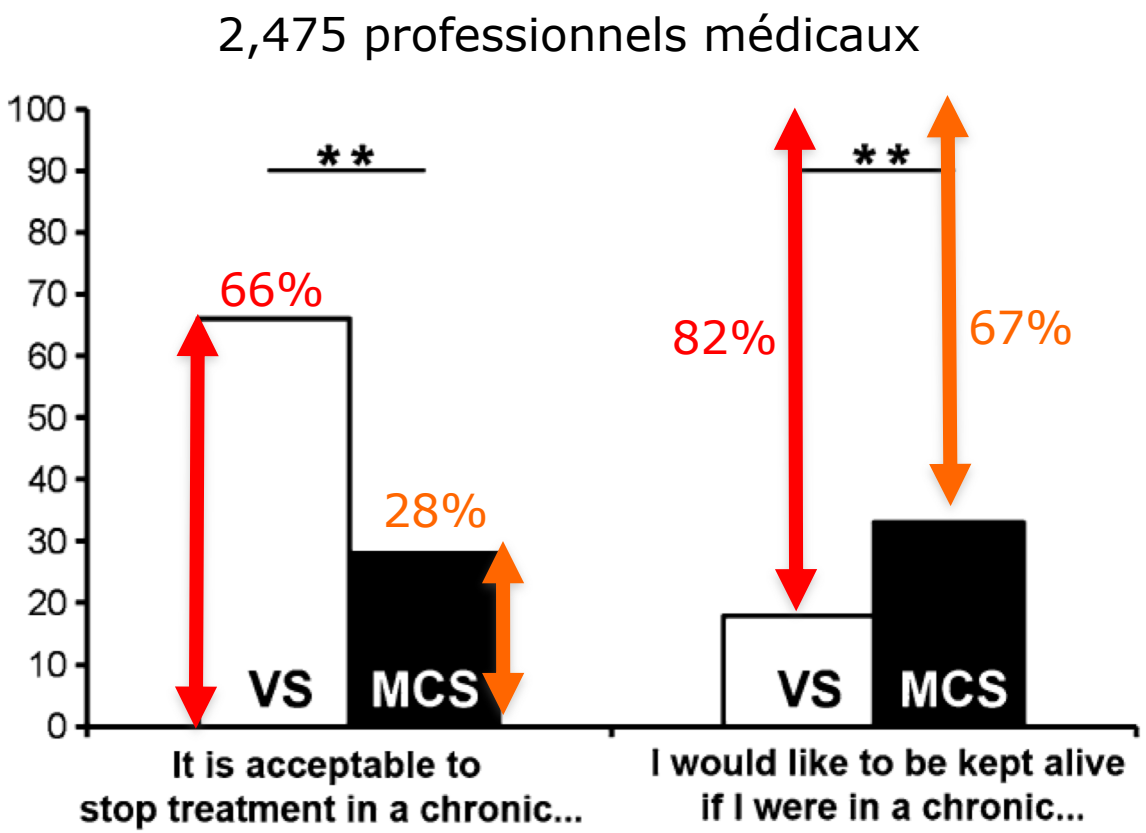
On peut arrêter les soins pour les patients quand ils…



Demertzi & Racine et al, Neuroethics 2012

Fin de vie

Opinions sur la fin de vie



ENR est pire que la mort pour
- Les patients: 55%
- Les families: 80%

ECM est pire que le ENR pour
- Les patients: 54%
- Les families: 42%

Demertzi et al, Journal of Neurology 2011

Mesurer la qualité de vie

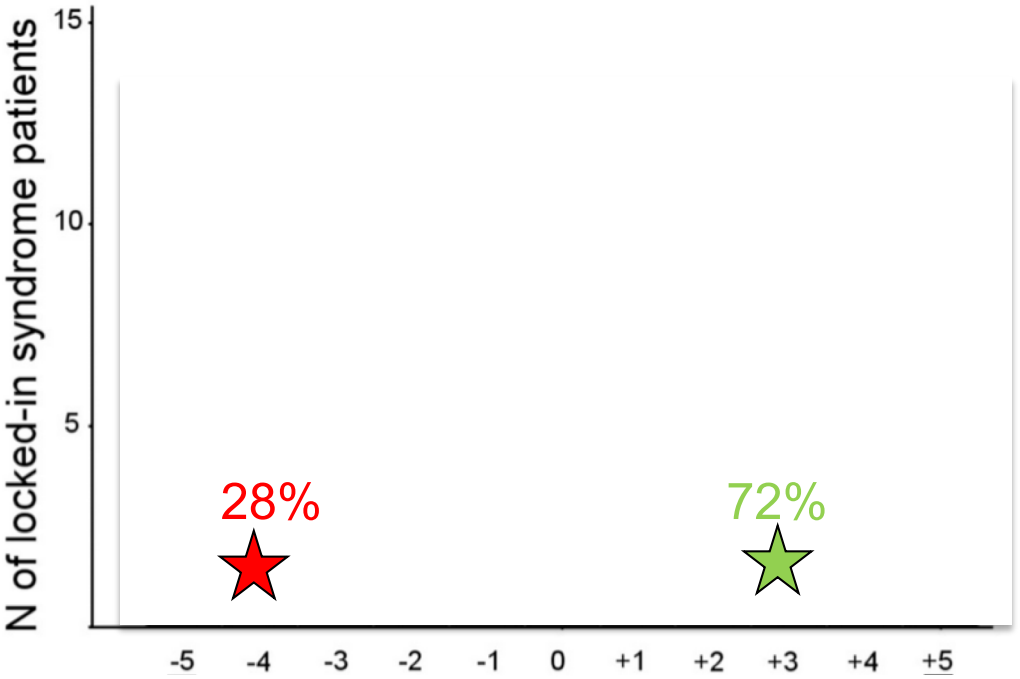
Open Access Research

BMJ open accessible medical research

A survey on self-assessed well-being in a cohort of chronic locked-in syndrome patients: happy majority, miserable minority

Marie-Aurélie Bruno,[1] Jan L Bernheim,[2] Didier Ledoux,[1] Frédéric Pellas,[3] Athena Demertzi,[1] Steven Laureys[1]

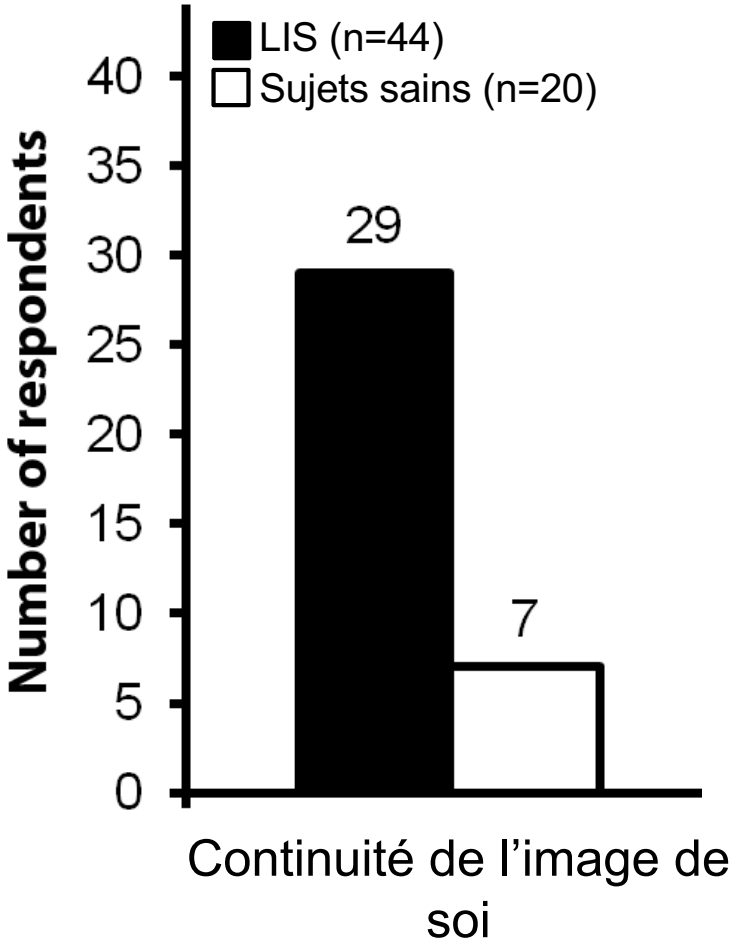
ALIS Association du Locked-in Syndrome



Pire période de ma vie

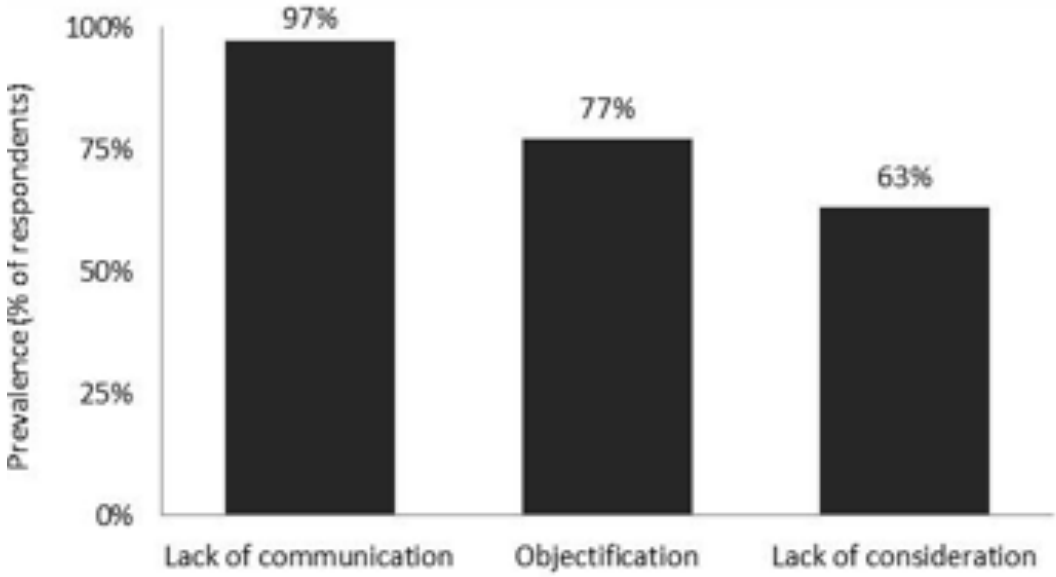
Meilleure période de ma vie

Le paradoxe de l'invalidité



Nizzi & Demertzi et al, Consciousness and Cognition 2012

Les attitudes inter-personnelles influencent la perception de soi



Nizzi, Blandin, & Demertzi, NeuroEthics in press

Comment prends-on la décision?

Directives anticipées: la déclaration écrite accomplie par une personne compétente en prévision de sa future incompétence, exprimant les préférences de traitement et la désignation d'un responsable légal formel

Le représentant légal a le droit de prendre la responsabilité de la prise en charge clinique du patient.

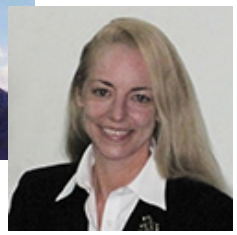
II/ elle doit protéger l'intérêt des patients selon les principes de bienfaisance et de non-malfaisance (càd, juger que le traitement en cours est vain sur la base de la probabilité de non-récuperation)

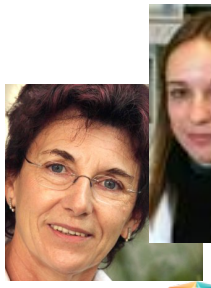
Lorsque les souhaits du patient ne sont pas connus, le représentant légal doit essayer de reproduire les préférences du patient en se basant sur son histoire et ses **valeurs personnelles.**

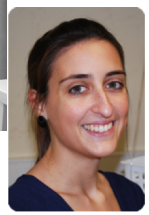
Quand cela n'est pas possible, les décisions doivent se baser sur des **marqueurs plus objectifs** qui déterminent ce qu'il y a de mieux pour le patient (par ex, probabilité de récupération, la perception potentielle de la douleur, l'impact sur la famille)

Demertzi, A., O. Gosseries, M.A. Bruno, C. Schnakers, A. Vanhaudenhuyse, C. Chatelle, A. Thibaut, M. Thonnard, and S Laureys. 2011. Désordres de la conscience: aspects éthiques. In Comas et états de conscience altérée, ed. C. Schnakers and S. Laureys, 157–164. Paris: Springer-Verlag.

Merci!







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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COMA SCIENCE GROUP

James S. McDonnell Foundation

Human Brain Project

esa European Space Agency

Inserm Institut national de la santé et de la recherche médicale

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