

French legislation on end of life decisions in patients with disorders of consciousness and massive physical disability

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French legislation on end of life decisions in patients with disorders of consciousness (DOC) is discussed, from one medical case that made French headlines. Some imprecise areas will be highlighted such as absence of early instructions, their value when they exist and the extreme variability of others judgment (family, caregivers, judges) about what we call a “deserving life”.

This requires knowledge of what “good quality of life” means for such patients who sometimes evolve into states such as “pseudo locked-in syndrome”.

Note that care givers and medical staff, when informed, operates a clear distinction, between the vegetative state and minimal consciousness. That underlines the pressing need to develop accurate methods to establish a conclusive diagnosis. However, for the time being, the clinical diagnosis is wrong in more than 30%, even 40% of cases.

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Oral communications

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A twenty-year longitudinal study of written production in a locked-in syndrome with bilateral corticopontic degeneration

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Keywords: Locked-in Syndrome; Language; Written production; Communication; Rehabilitation

Patients in locked-in syndrome show normal or near normal mental abilities that contrast with the limited motor capacity that hinders voluntary communication. However, eye movements and blinking are usually preserved and can be used to establish a communication system. We report an exceptional case of locked-in syndrome. The aetiology was basilar thrombosis consecutive to a cervical manipulation. In addition, brain MRI performed 23 years later evidenced a ventral pontine stroke with bilateral corticopontic degeneration. In this study, the patient was able to produce written output using a chin-controlled Morse system decoded by a computer. A detailed linguistic analysis of text written over 20 years by the patient was carried out. The data demonstrate that improvements in language performance can be observed even in patients with brain lesions in areas associated to high-level cognitive processes. The data shows a decrease of typing, grammatical and lexical errors over time, a use of less frequent words, and an increase of more complex linguistic structures. This paper adds to previous findings, confirming the value of daily practice and rehabilitation to enhance quality of life in this group of patients.

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Evolution after a 6-year interval of the quality of life (QOL) of a population of locked-in syndrome patients (LIS):

Determinants

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Keywords: Locked-in syndrome; Handicap; Stroke

Introduction.— To estimate the course of LIS patients' QOL in a 6 years interval.

Patients and methods.— A questionnaire was sent by ALIS in 2007 and in 2013 to 67 LIS patients. Data collected were: age, gender, aetiology and LIS duration, autonomy for the displacements, communication devices, medical devices, chronic pain occurrence, euthanasia request. QOL has been estimated by the ACSA (Anamnestic Comparative Self Assessment).

Results.— Sex ratio: 41 men/26 women, average age 53 years. The main aetiologies of LIS were: stroke (51), trauma (8). The average duration of the LIS was 13.7 years. Among 30 patients having informed the QOL in 2007 and in 2013, the QOL has not varied significantly after 6 years ($P=0.643$). The remaining data from 2013 show: 75 living place in residence and 25% institution; 58.3% could communicate with a Y/N code and 50% had a computer communication device; 62% were autonomous with an electric wheelchair. Concerning medical devices: 41.7% had a gastrostomy, 29% had a tracheotomy and 12.5% had a permanent urinary probe. A total of 54.2% had chronic pain, 58.3% envisaged resuscitation in case of necessity, and none had a wish of euthanasia.

Discussion.— This work demonstrates that the QOL of the LIS patients is preserved and stands still through time.

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Posters

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Clinical and neurophysiological evaluation for patients in PVS or MCS: Feasibility and interest

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Keywords: Vegetative state; Minimally conscious state; Event-related potentials

Clinical diagnosis for patients presenting a permanent vegetative (PVS) or a minimally conscious state (MCS) is difficult and not accurate [1]. Recently developed techniques may become an important help to the clinician for the evaluation of such patients.

We evaluated the feasibility of a clinical and electrophysiological assessment for patients hospitalized in a PVS/MCS unit: Coma Recovery Scale-Revised [CRS-R] [2], Wessex Head Injury Matrix [WHIM] [3], auditive evoked potentials and P300 event-related potentials [4]. Ten patients benefited from the evaluation: 3 PVS, 2 MCS patients, and 5 patients that had clinically emerged from MCS (WHIM: 36 ± 21 ; CRS-R 14 ± 7). P300 was detected among 6 patients, absent for 3 patients, uninterpretable for 1 patient. Mean WHIM score for the patients

