Altered states of consciousness: the ethics of death

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Should treatment keeping alive patients in a vegetative state or in a minimally conscious state be stopped? Would doctors and nurses accept to survive in the stranglehold of such states? Is a vegetative state worse than death? The Journal of Neurology has recently published the results of a vast enquiry carried out by the University of Liège’s Coma Science Group. Between September 2007 and October 2009, Professor Steven Laureys, the Director of the Coma Science Group at the University of Liège’s Cyclotron Research Centre (CRC), took part in 59 medical and scientific conferences and congresses in Europe. At the end of each of these events he systematically handed to the participants a document consisting of 16 questions centred on ethical considerations related to the vegetative state (VS), the minimally conscious state (MCS) and locked-in syndrome (LIS). Beforehand the people questioned had received detailed information concerning these particular states of consciousness. They were then asked to respond either 'yes' or 'no' to the questions they were set. To enable a more nuanced interpretation of the results five demographic pieces of information were collected from each participant: age, gender, nationality (32 countries divided into 3 geographical zones - Northern, Central and Southern Europe), profession and religious beliefs - more specifically whether or not they believed in God and subscribed to an institutional religion (Christianity, Islam, Judaism, etc.), without necessarily being practicing. It was within this framework that Athena Demertzii, a Greek neuro-psychologist currently working on her doctoral thesis at the Coma Science Group, analysed the responses provided by 2,475 doctors and members of the paramedical sector (1) (essentially nurses) to 6 out of the 16 questions posed. This work has recently been the subject of a publication in the Journal of Neurology (2).

Stopping treatment

Let’s get to the heart of the matter. Some 66% of the people asked (3) judge it acceptable to stop treatment (artificial nutrition and hydration) for patients plunged into a chronic vegetative state (over a year), whilst only 28% of the respondents (27% of the doctors, 23%
estimate that this measure is justified when addressed to patients in a minimally conscious state who had fluctuating residual consciousness combined with an inability to communicate their thoughts.

When the criteria of minimally conscious states were defined in 2002 by Joseph Giacino, of New Jersey Neuroscience Institute, a number of neurologists doubted the pertinence of introducing into the nomenclature a new clinical entity which, in their eyes, was merely a sub-category of the vegetative state. ‘They couldn’t see the value of creating a specific entity for patients who remained very handicapped, to the point of not being able to communicate,’ explains Steven Laureys.

These neurologists were wrong, and for several reasons. The first is that we today know that the chances of recovering for subjects in a minimally conscious state are better than for their counterparts in a vegetative state. Next, the studies carried out notably by the Coma Science Group have shown that patients in a minimally conscious state had very different cerebral activations depending on when they were submitted to auditory stimuli without emotional connotations (nondescript noises) and which is not emotionally charged (the cries of a baby, stating their name, etc.). These activation patterns were similar to those of normal subjects, whilst this was not the case for patients in a vegetative state. A yet more decisive element, because it is of capital importance at the level of medical ethics, was revealed in September 2008 when *The Lancet Neurology* published an article (4) by the Coma Science Group researchers. In it the authors showed that patients in a minimally conscious state feel pain.

The results to the questions related to stopping healthcare underline that the medical and paramedical body, when it is informed, makes a clear distinction, at the level of ethical issues, between the vegetative state and the minimally conscious state. This once again renders null and void the initial opinion of numerous neurologists, at the beginning of the years 2000, and brings out the necessity of acquiring the means necessary to establishing an irrefutable diagnosis. Because, as several studies have shown, a clinical diagnosis established ‘at the bedside’ is mistaken one time out of three, or even in around 40% of cases. According to Steven Laureys, the systematic use of a standardised and sensitive behavioural scale, such as the (Coma Recovery Scale-
Revised - CRS-R), can help to reduce this type of error, or at least limit the uncertainty related to diagnosis. Moreover this diagnosis could be refined by using functional neuro-imaging techniques, a practice which people are today endeavouring to lighten.

Discordance

Two other questions analysed by Athena Demertzi had the outcome that the participants wanted to maintain some reserve should they be plunged into a chronic vegetative state of a chronic minimally conscious state. In the first case only 18% amongst them (19% of the doctors and 12% of the paramedical personnel) wish to be kept alive. In the second case, 33% (doctors: 35%; paramedical staff: 24%)

How to explain the gap between the doctors and the paramedical staff? The study has provided no response on the subject. Steven Laureys nevertheless offers an hypothesis: more often present at the patient’s bedside, nurses perceive better the daily reality and the potential suffering of the patients, whilst doctors reason more in terms of the chances of recovering.

What is more striking for the Director of the Coma Science Group is the discordance on a statistical level between the measures the medical and paramedical personnel would want to benefit from should they themselves 'sink' into an altered state of consciousness and those which they judge acceptable for other people. Let us recall the figures: if 66% of the people asked are in favour of stopping treatment for patients in a chronic vegetative state, 82% would wish not to be kept alive in analogous circumstances. And the gap widens when it is the case of a minimally conscious state: 28% versus 67%. ‘The irreversibility of death and moreover the fear of legal proceedings can doubtless explain in part why doctors are not always inclined to grant their patients what they would wish to benefit from themselves,’ says Steven Laureys.
And he regrets this attitude: 'Certainly society should protect the weak but it should also take care to respect each person’s right to prefer death to a life they consider undignified or unacceptable. Our study published in the Journal of Neurology, and another, to be published, which we have carried out with the general public, clearly underlines that the majority of us do not want to live in a state of altered consciousness. The medical body needs to do some work on itself, because for me it appears neither moral or ethical to not grant others what you would like to be applied to yourself.'

In order to clarify each situation and avoid tragedies, such as that of Terri Schiavo, which led a family and a country - the United States - into a sterile and sordid polemic in 2005, the Director of the Coma Science Group pleads in favour of living wills or other anticipatory documents, a way of signposting the final journey (read **Declaring means anticipating**).

The detailed analysis of the results provided for the above mentioned questions highlights significant differences between the North and South of Europe. The South is much more reticent as to the stopping of treatment and, as might be supposed, it is the nature of religious convictions which appears to be the variable which takes the form of the greatest predictive value concerning the subject. Central Europe is in an intermediary position. It can furthermore be noted that men are more favourable than women to stopping treatment for patients in a vegetative state or a minimally conscious state, and that the older people are the less this outcome is accepted.
Worse than death

Let us now address the final two questions which Athena Demertzi's analyses focused on. In the eyes of 80% of the sample it is worse for an individual's family if s/he is in a vegetative state than if s/he was dead; on the other hand no more than 55% of respondents consider that it would be better for the person to die than to remain a prisoner of such a state. These percentages can be easily understood in the sense that, deprived of consciousness, the patient in a vegetative state doesn't suffer, contrary to his/her family.

On the other hand if 54% of the people who responded to the questionnaire consider the minimally conscious state as being worse for the patient than the vegetative state, this percentage falls to 42% when they consider the same question from the point of view of the family. 'Certain families content themselves with a few signs of residual consciousness, such as a smile to a mother or a father,' comments Steven Laureys. 'And it is precisely this residual consciousness, linked to the impossibility for a patient to express his/her thoughts or feel physical pain, which leads certain people to consider that for the patient the minimally conscious state is worse than the vegetative state.'

On this point, as for the preceding one, there are no borders: there is no significant difference between Northern, Central and Southern Europe.
(1) The sample was made up of around two thirds doctors and one third members of paramedical personnel.
(3) On this point the percentages are identical for the two major components of the sample, - doctors and paramedics.