FROM THE INSIDE

Buying time to save a life: a 3-month “call in the dark for awareness”

A moral dilemma in predicting consciousness recovery

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Might the science of prognosis in medicine have a philosophical meaning? In particular what about the neurological prediction of coma recovery, whilst we are trying to analyse a state of consciousness that we can hardly describe as phenomenology and not explain in a classical mechanistic view? Up to what point could the confidence we have in such prognosis—in clear conscience—legitimately modify the future of a piece of the mankind we have in our charge, represented by a single individual destiny? What kind of human decision, imprinted with doubt by nature, can make a hospital bed a transient stage to another step for further life (even in a clinical state we would have refused for ourselves) or a shroud?

We would like to give some clues to thinking about these issues, based on a real clinical situation we met a few months ago in our intensive care unit and whose long-term outcome gave us some insight into this topic.

Amyotrophic lateral sclerosis (ALS), the disease we are dealing with, is one of the most pitiless for a physician. ALS illustrates our constant failure to understand physiopathology and to treat a protracted life-threatening condition. Is it therefore reasonable to propose tracheostomy and prolonged mechanical ventilation in this setting? Tracheostomy is commonly proposed in cases of either complete dependence on noninvasive ventilation (spinal ALS) or interface issues reducing tolerance of noninvasive ventilation (bulbar ALS). A normal cognitive ability and a strong motivation are required and both of them must be consistently verified over time.

A fair attitude consists in honestly presenting the disadvantages of tracheostomy with clear information, which should be adapted to the patient's social and intellectual background. In some cases, this process could lead one to advise against invasive ventilation. It is yet noteworthy that some physicians, whose first aim is maintaining good overall health (or the perception they have of it) without any disability, adopt an utilitarian position consisting in not proposing tracheostomy at all, even in classical indications.

Admitting this heterogeneous state of medical opinion, what does one do when a patient becomes suddenly unable to confirm a decision he/she had previously accepted? How could we consider the previous acceptance made at the time the patient was fully conscious and competent as long as he/she remains comatose after a severe brain insult? Should we wait until the recovery of full brain function?

This happened to a 30-year-old French man, in whom the spinal form of ALS was diagnosed 3 years ago. He was quadriplegic and had been receiving noninvasive mechanical ventilation for more than 1 year. He always refused to have a tracheostomy. After transient invasive mechanical ventilation for gastrostomy, as he faced death due to acute respiratory failure in the weaning period, he spontaneously announced that he had changed his mind. The tracheostomy surgery was not organised immediately because he chose to wait for another respiratory deterioration. Unfortunately a hypoxic pneumonia occurred nightly at home, with no signs of distress but with cyanosis and coma. He was intubated and transferred to our ICU. The first measurement of oxygen saturation was as low as 50 % and had probably been at that value for many hours before but without cardiac arrest. This rare purely hypoxic coma was associated with atypical leucoencephalopathy on the MRI we performed.

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A debate ensued in our medical team. Should we still follow his will to have a tracheostomy? The first consensual decision at this point was to require a complete cognitive and communicative recovery (taking into account the ALS disability). Should we go a step further in the possibility to describe our next strategy to his relatives? We tried to predict the likelihood of awakening by using electrophysiological data. As cortical components of both somesthetic and cognitive auditory evoked potentials (mismatch negativity, MMN) were present, the probability of no awakening was highly unlikely. However, we had no relevant tools to describe the final cognitive status more precisely. After many heated discussions including medical and paramedical teams, family, hospital administration and external expert advice it was agreed that only a more prolonged waiting time would be able to confirm the nature of his recovery. Nonetheless we planned to withdraw futile supportive care after 3 months in the absence of a complete awakening. This strategy was explained to his family (wife and mother) and therefore accepted with their assurance to bring him back home in case of success. This atypical medical situation was debated weekly and the “wait and see” strategy was confirmed weekly.

Progressively the patient arose from coma to a vegetative state after 10 days. One month after the insult, he began to fix his attention in a mirror, which fulfilled the consensual definition of minimally conscious state according to the Coma Recovery Scale-revised. This positive dynamic helped us to stay on course. Finally 2 months after admission, he followed simple commands with functional palpebral muscles (and to a lesser extent with his mouth). As he communicated with a Yes/No code, he was asked whether he maintained his previous advance directives. After few days to think about it, he confirmed his desire to have a tracheostomy. A posteriori, our hazardous strategy was validated by this sole gold standard for prognosis, i.e. the clinical evolution over time.

An 8-month complete hospitalisation was necessary to organise his discharge to home but he was finally able to live with his son and wife while communicating with an eye-tracking system. This communicative strategy was first imprecise because of sedative effects of combined anxiolytic and analgesic drugs. It improved further after visual fixation default related to pregabalin treatment was corrected with the interruption of the medication.

A serious confounding factor in this story consists in the speciality of the senior in charge (a neurologist in this ICU). Despite being in the minority, his knowledge regarding the limits of the prognostic tools and the few clinical clues in favour of a small but relevant clinical improvement together with his hope to optimize future

communications using a brain–computer interface have given some consistency in a 3-month-long “call in the dark for awareness”.

Overall, this medical story has nothing especially new per se. We have used the available neurological prognosis factors and considered their limits. The most questionable aspects of our strategy consist in the difficult medical context, which would have led many caregivers to refuse prolonging such a disabled life. This is usually based on two reasonable opinions: (1) everyone’s personal projection in such a situation, and (2) the anticipated suffering of the close family. Our sole objection for not following this position consisted in our aim to respect the patient’s free will, as expressed voluntarily in advance directives. Even if tracheostomy is not actually recommended and proposed everywhere, a young motivated patient remains the only tolerable indication. In an ethical view based upon equity, neither ALS nor a reversible coma could release a medical team from respecting the patient’s choice.

Nonetheless, the utilitarian proposal previously enounced was regularly opposed in the ethical discussion. Such a justification might be emphasized now. From an individual point of view, even if it seemed to have been the final result of a free-will decision, one may wonder whether this tracheostomy was a good alternative for this patient. Was the limited functional outcome we could merely offer to him a self-sufficient reason for the psychological harm his family had to support in waiting for his awakening and in further postponing an ineluctable loss? Even for his own person, was it fully legitimate to provide his conscience a way to avoid a necessary face to face with death? At an ultimate point, why should we help him maintaining a chimeric instinct of individual perpetuation?

Yet, at the date of the critical choice, we assumed not to defend such a position, which could have led one to cast some doubt on the accepted (but voluntarily restricted) indications of tracheostomy in ALS. As such pains are intrinsic to all other similar conditions, we chose to base our reasoning on the relative value of his previous clinical status and not on an absolute idea of what the good would be here. We decided to respect the patient’s will, with the only hope that, instead of doing anything good, we still let him choose through coma what he thought to be the less bad for himself.

“But what is the cost we could accept?” may ask both society and institutions. Indeed, a larger population-scaled point of view forced us to consider that one ICU bed was being occupied for so long in order to maintain the hypothetical hope of a low quality of life. The “next-patient” way of thinking drove us to imagine the theoretical possibility of 100 % of miracle-waiting patients in

every bed at the same time. According to this *reductio ad absurdum*, it might lead us to refuse some cases with far better prognosis.

These arguments shall yet not be applied to such individual matters of life or death. Firstly, all the expected terms (ALS, young patient with a previous opinion in favour of tracheostomy, hypoxic coma with no cardiac arrest, presence of both somatosensory evoked potentials (N20) and MMN) are rare enough to change bed management. Secondly, we did not choose a hopeless neurophysiological pattern of coma to wait for a miracle. We simply assumed to confirm in a very particular situation that awareness is about to reappear if MMN is present.

Nonetheless, a distributive mindset implied the need to calculate the economic cost of such a management, first in ICU, then at home, with at least thousands of euros spent. Any ethical decision could then be rather taken according to an epicurean *metriopathia*, balancing the population's sufferings we could have avoided through public health care programs with the cost of one individual care.

We decided to not answer these questions, just because this has already been done. It was done at the very onset of intensive care medicine when home-care networks were institutionally organized to manage respiratory failure in the long term. In a way, every chronically mechanically ventilated patient is in such a situation: a particular and extreme disability, for which our modern society boasted about caring anyway. According to Leonetti's law, in France such an economic justification is not an argument that can be used for limitation of care processes. The French Intensive Care Society's (SRLF) ethical

guidelines consider this point to be regarded beneath the individual interest of the patient. As we assumed these questions to be politically resolved (in our age, but not for ever), we simply tried to maintain this specific case using the very same reasoning as for every other patient, in spite of coma and ALS. Our decision had no ambition of jurisprudence. But we assumed that such an extreme illustration could give new insights into such dramatic debates about what we have to fight for.

In other words, after such an experience, every author would be committed to take exactly the same decision if this particular case arose again. But we would humbly say that, even with such a cautious and individually driven attitude, we are still not able to respond to the following questions: in waiting or stopping patient management are we really reading the future in our medical devices? Or are we just writing ourselves the end of the story, in choosing one of these two opposite actions?

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Acknowledgments

The authors would like to thank Prof. J. Luauté for his precious advice during the management of this patient, Dr. Maité Castro for her analysis of the MMN data and Dr. Nathalie André-Obadia for her help in the neurophysiological process.

Compliance with ethical standards

Conflicts of interest

On behalf of all authors, the corresponding author states that there is no conflict of interest.

Published online: 29 February 2016