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Withdrawal of clinically assisted nutrition and hydration decisions in patients with prolonged disorders of consciousness: best interests of the patients and advance directives are the keys

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Comment on: "Back to the bedside? Making clinical decisions in patients with prolonged unconsciousness" (Wade, D.) & "Can 'Best Interests' derail the trolley? Examining withdrawal of clinically assisted nutrition and hydration in patients in the permanent vegetative state" (Fritz, Z.)

In this issue of the journal, Dr Fritz and Dr Wade raise the controversial issue of the withdrawal of clinically assisted nutrition and hydration (CANH) in patients with disorders of consciousness (DOC).[1 2]

Dr Fritz, in an elegant demonstration, illustrates how it could be in the best interests (referring also to the Best Interest procedure as described in the Mental Capacity Act)[3] of the patient to stop his life promptly (ie, by injection of lethal drugs) to save another patient's life through organ donation rather than considering withdrawal of CANH. Although the underlying reasoning is very relevant, I would like to point out that we are here dealing with several issues that the author might have mixed up. First, we are questioning the patient's right to an autonomous choice around organ donation and their right to refuse or to withdraw medical treatments. Moreover, although a special focus was made on patients with DOC, we are clearly questioning the more general and touchy subject of organ donation from the mentally incompetent patients in general (ie, also the communicating ones) and their right to euthanasia. Unfortunately, these ethical dilemmas have been subject to vast debates and even (or moreover) in Europe, no consensus exists, with diametrically opposed points of view from country to country, from the most permissive to the most restrictive laws.[4] While, in some cases, it could be seen as morally acceptable to transplant organs from incompetent people (as the mother and son example from this paper), it is also undeniably imperative to provide strong safeguards to prevent abuses that could arise from an utilitarian perspective when debating the legitimacy of withdrawing CANH in patients with a DOC. Hence, I am not convinced of the path endorsed by the author to solve the problem. In an attempt to answer the question, we can look to the existing legislation in Belgium. Since the 28th of May 2002,[5] it is allowed for any adult to give advance directive to authorities in order to engage a procedure of euthanasia (ie, administration by a medical doctor of lethal treatment) in the event of his incompetence. Moreover, euthanasia does not legally and medically exclude organ donation.[6] Nevertheless, it must be said that very few people fulfil the entire procedure. How many times haven't we heard 'Living like this would have been unbearable for him'? or 'when we talked about this eventuality, he said that in this situation, he would rather die', but no advance directive was recorded to the authorities. The reasons? Among others, the lack of large scale information about this law and advance directives, and about prolonged DOC. Very few people know what is to expect as prognosis and, more importantly, as functional outcome from these conditions, and simply don't know what lies behind the words 'unresponsive wakefulness syndrome' or 'minimally conscious state'.

Yet, Derick Wade reviews, in his interesting contribution, that this dichotomy has an over-rated importance in the foundations of the judgement process by the court in UK when debating the withdrawal of CANH in these patients. As mentioned by the author, the current state of knowledge fails to determine structural or functional requirements for consciousness to emerge. What is the point knowing if the patient is fully unconscious or not? If he is not, could you infer the content of his consciousness, or could you then understand 'what is it like to be minimally conscious?'[7] Would you be able to find a way for him to communicate his will? Definitely not to date. The only purpose in determining it would be to determine more accurately the prognosis in term of survival as of functional recovery. After several months (3 months for an anoxic aetiology, 12 months for a traumatic aetiology of the DOC[8]), it is known that the functional outcome will not be very different from the functional level to date. We cannot infer on the content of consciousness, but we know the expected functional outcome. Consequently, this must be the centre of the discussion in decision-making meetings. Is this decision in accordance with the best interests of the patient (in the meaning of the British law, or in its wider sense)? This is also what is often experienced in any life-threatening decision that has to be taken in medicine and (fortunately) this does not require the intrusion of justice professionals in the medical sphere. This shouldn't be the case either in these situations. The court should be involved only in very specific cases, for example, in the event of severe disagreement between the relatives of the patient. I don't mean that we should go back to a paternalistic position of the medical team but its role is to validate the decision that emerges from a 'best interest meeting', whatever the level of (un)consciousness of the patient and in as much accordance as it can be with his inferred wills (substituted judgement). In this process, the involvement of the relatives is mandatory. And what we are expecting from them is the best possible knowledge of the point of view of the patient. 'Would it be bearable, for the patient, to live this way? (ie, with this level of functional recovery)'. If the answer is yes, (ie, his present level of functional recovery would be sufficient for him to find meaning in his life), CANH should probably be maintained. If it isn't the case (ie, if he had the possibility to communicate his will, he wouldn't have accepted to live in such a level of dependence), then CANH withdrawal should definitely be considered. There are of course no guidelines for this purpose, but the author, in an attempt to provide some, pinpoints actually the fact that, in order to have coherent decisions inside a country and across countries, specialists of the field of disorder of consciousness should gather to propose guidelines of management for withdrawal of CANH; this would make it easier for authorities to return decisions to teams at the bedside.

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