# Discontinuation of hydration and nutrition in vegetative or minimally conscious state: no straightforward answer

*For this reason a man will leave his father and mother and be united to his wife, and the two shall become one flesh.*

Matthew 19:5

**To the editor** I diligently read a paper by Pawlikowski et al[1] that discussed discontinuation of hydration and nutrition in vegetative or minimally conscious state. The authors emphatically opposed the discontinuation of hydration and nutrition based on a recently disputed case of a Pole (RS) with severe brain damage, resulting from a prolonged cardiac arrest that lasted at least 45 minutes.

There is, however, no straightforward solution to the problem. First, from the strictly medical point of view, there is insufficient evidence to draw firm conclusions on the impact of clinically assisted hydration or nutrition in the last days of life.[2] It may supposedly offer some patients comfort, and potentially relieve perceived thirst (assuming it is present); however, it may lead to fluid retention, heart failure, abdominal distension as well as pose the risks associated with placement of a nasogastric tube or infusion devices. Second, discontinuation of hydration and nutrition is not a nondebatable ethical issue, even in children.[3] It is also worth adding that, albeit in another context, refusal of treatment with the awareness that death will soon follow is not suicide, according to international medical ethics, and forced feeding may be considered a torture.[4]

In this particular case the healthcare provider application for food and hydration be withdrawn and to provide appropriate palliative care (according to the United Kingdom legal and medical standards), in order to maximize his dignity and ensure no unnecessary suffering in a patient lacking capacity to consent or refuse medical treatment was supported by RS's wife, but was opposed by his mother, 2 sisters, and niece, who lodged an appeal against the decision made on December 31, 2020, in which the judge rejected a declaration that it would be in RS's best interests to receive clinically assisted nutrition and hydration. The judge also refused to order that RS should be transferred to Poland for further treatment. Similar application by the mother and sister was rejected also by the European Court of Human Rights on December 24, 2020. The details of the Judge's decisions are publicly available and may be found in the list of England and Wales Court of Protection Decisions (see University Hospitals Plymouth NHS Trust).[5]

The judge rejected the suggestion that RS should be moved overseas (to Poland) based, among others, on the following premises: 1) patient's transport was associated with significant risk of death; 2) "it would be deeply uncomfortable for RS, far worse than being nursed on a hospital bed"; and 3) "it is unthinkable that he should be moved against the wishes of his wife and children."

Since it was impossible to ascertain RS's wishes, the Judge had reached the decision that it can be ascertained from his wife's reports, rather than based on the claims made by his mother and sister of RS's beliefs and pro-life convictions. It is important to add that, according to testimonies, RS had relatively little contact with his Polish family, for example has not seen his sister who lived in England since about 2011 and had little contact with his mother and sister in Poland. Moreover, it is perhaps prudent to assume that RS accepted United Kingdom's ethical and legal medical standards, being a resident there from 2006.

Given the abovementioned medical[2] and ethical[3] uncertainty of what decision would be in the best patient's interest, and patient's inability to express his will, this particular case raises a lot of ethical questions that were not addressed by the position statement by Pawlikowski et al[1]:

**1** Should wife's reports be rejected in favor of declaration of the other members of the family in the process of ascertainment of patient's preferences, and why?

**2** What would be the ethical approach to the ethical dilemma of wife's suffering, if her testimony was ignored, and how this relates to the man and

wife relationship as perceived by patient's Catholic faith (Matthew 19:5)?

**3** How should ethical dilemmas related to the risk of death during transport be handled?

**4** Should ethical system in the country of origin (Poland) prevail over the ethical system in the country of residency and why?

**5** Should the use of artificial nutrition and hydration towards the end of life be unequivocally recommended without sufficient clinical evidence?

## ARTICLE INFORMATION

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**Authors' reply** We are very grateful for all the important comments and questions raised in Piotr Szymański's correspondence.[1] We would like to note that our position statement relates to the feeding and hydration of patients in vegetative state (VS) or minimally conscious state (MCS) without referring to the management of patients in end-of-life care requiring advanced life-supporting medical devices (eg, a ventilator) or after brain death.[2]

Referring to the first question, regarding the omission of the spouse's opinion, we want to emphasize that we do respect the opinions of the patient's wife and other relatives without prejudging their importance and that our document focused mainly on the axiological assumptions underlying the decision of the court. Therefore, we did not analyze the wife's opinion, as it was in line with the court's decision, but we noticed that the view shared by the patient's sister and mother was inconsistent with the court's reasoning. We are aware of the complexity of a situation in which the patient's will must be reconstructed based on the opinion of relatives. In many similar cases, such a reconstruction was difficult due to lack of unanimity among family members (eg, Vincent Lambert case, Terri Schiavo case). There were also cases where the court accepted the mother's and sister's objections to the wife's request to stop tube feeding and hydration (eg, Michael Martin case, Robert Wendland case).[3] The variety of these cases shows that there is no legal consensus as to the prevalence of opinions of some family members over others in formulating the best interest of patients. The raised question of marriage from a Catholic perspective and the Gospel passage quoted (Matthew 19:5) seem to be irrelevant here. RS and his wife were in a civil marriage, but not in a religious (sacramental) marriage, due to obstacles to the annulment of the wife's previous marriage (point 18).[4]

Regarding the question concerning the ethical aspect of transport, it should be noted that the ethical assessment should encompass not only the risk of the action as such but also its goal and missed opportunities. The court was aware that RS could survive without a ventilator for "up to 5 years or more" and that after the "removal of nutrition and hydration he would die within a matter of a couple of weeks" (point 12 of the judgement).[4] In this situation, transport to another center gave the patient a chance to continue his life (and even to improve his condition). Thus, it seems that the benefits of transport outweighed the associated risks, which should be minimized with professional care.

As to the issue of which ethical system should prevail (country of origin vs country of residency), it seems that the main question is not about the prevalence of one national ethical system over another, but about what ethical principles should shape decisions about the patient: respect for every human life or assessment of human life depending on its quality. Also, we are not convinced that "it is reasonable to assume that RS accepted United Kingdom's ethical and legal medical standards, being a resident there from 2006." The patient did not renounce his Polish citizenship, nor did he apostatize from the Catholic Church. In fact, he continued to regularly attend Catholic services. The protest statement of the Catholic Bishop of Plymouth also included the description of the existing ethical differences within the British society regarding the RS case. In a pluralist society, respect for the views of minorities (in this case, the Catholic minority in the United Kingdom) should be a standard, especially if they mean broader protection of fundamental human rights.

We agree with author and the cited review[5] that parenteral hydration in the care of dying patients may be inconsistent with the welfare of some patients (due to fluid retention or heart failure risks). However, for others it may be beneficial by relieving symptoms (eg, delirium). Thus, this decision should be always carefully individualized.

However, our position statement does not apply to this population of patients. In the case of patients in a VS / MCS, nutrition and hydration do fulfill their physiological functions. We are not aware of any reliable scientific evidence that feeding and hydration withdrawal in VS / MSC benefits patients. Therefore, it may be assumed that such judicial decisions are based more on individual beliefs and convictions than on scientific evidence.

In our opinion tube feeding and hydration in VS / MCS should be treated as basic care and not as a therapy that can be stopped on the grounds of persistence. The axiological assumptions of the RS judgement carry the risk of "slippery slope" in terms of protecting the lives of deeply disabled people, distorting the goals of medicine, and deepening discrimination based on health status. We agree that there is no straightforward solution to the problem, but we believe that any doubts should be resolved according to the principle of in dubio pro vita.

## ARTICLE INFORMATION

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