

Virtual Mentor

American Medical Association Journal of Ethics
May 2007, Volume 9, Number 5: 340-344.

Clinical case

Is artificial nutrition and hydration extraordinary care?

Commentary by Kenneth Craig Micetich, MD

Mrs. Henderson's eyes darted to the side of the bed as her nurse attempted to obtain an arterial blood gas. This response slightly startled John and made him consider whether or not he was causing her discomfort. John had often found it unsettling that she appeared awake, her eyes open, spontaneously moving her arm or leg, but it was a thought he repeatedly tried to dismiss.

Mrs. Henderson had been a resident in the ICU at Sacred Heart Hospital for seven months after a serious motor vehicle crash that claimed the lives of two of the four passengers. Her husband had been driving and had sustained only minor injuries. Mrs. Henderson, however, had suffered severe damage to her brain as a result of hypoxia secondary to cardiopulmonary arrest at the scene that ultimately caused her to lapse into a coma.

Her physician, Dr. Bernard, had informed Mr. Henderson after several months that, given his wife's MRI and physical exam, she most likely was no longer in a coma but in a persistent vegetative state (PVS). Dr. Bernard asked Mr. Henderson to consider goals for his wife's care.

"What do you mean...goals?" Mr. Henderson asked, slightly annoyed.

"I know this must be very difficult, Mr. Henderson. But now may be the time to consider what your wife would have wanted should she be in a position such as this. Did she ever discuss any of her wishes with you? Was your wife religious?"

Mr. Henderson said, "Yes, my wife was very explicit about a situation like this. She had even written out a living will that specified that she never would want to be kept alive artificially with food and water. I will bring you the living will tomorrow when I come in."

Then Mr. Henderson remembered something about a speech that the pope had made not long ago, in which he seemed to say that artificial nutrition and hydration were mandatory for Catholic patients in PVS. Upon realizing this, Mr. Henderson turned to Dr. Bernard and said, "Doctor, my wife was a devout Catholic, and because the pope seemed to require all Catholics to be given artificial food and water, I think my wife would now want these measures given to her."

Dr. Bernard was now perplexed. It appeared to him that a patient's signed living will to forgo artificial nutrition and hydration would supersede the claim by Mrs. Henderson's husband that she would want these measures given to her. He was aware that the local bishop of the diocese had recently come out with a strong statement in support of the pope's speech, but Sacred Heart Hospital had not as yet officially reacted to the bishop. What was Dr. Bernard to do? Was he to follow the living will and discount the pope's and bishop's statements, or was he to follow Mr. Henderson's interpretation of what his wife would want in light of the recent ecclesial documents? Dr. Bernard wanted to accommodate his patient's request even if this might go against church and hospital policy. He decided to give himself a day to think about all the complexities of this case.

Commentary

Most people understand that patients with irreversible liver failure or with incurable metastatic cancer are terminally ill and that these patients will die despite sophisticated technological interventions. The right of these patients and their families to forgo life-prolonging treatments deemed burdensome and without reasonable hope of benefit is well-established. The treating doctor historically has been able to recommend limiting interventions when failure of the heart, liver or lungs leads to severe physiological derangements that are incompatible with life and cause the death of the patient.

On the other hand, society seems to find it difficult to address brain failure or dysfunction caused by severe primary central nervous system disease, trauma or anoxic insult. Such dysfunction may impair consciousness but does not directly produce the dire consequences associated with severe system breakdown seen in heart, liver or lung failure. Absent significant brain edema with herniation, one does not usually die directly of the brain trauma but of the consequences of loss of neurological function—hypoventilation, aspiration pneumonia, pulmonary emboli, and malnutrition and dehydration due to an inability to eat and drink. Thus supportive treatments such as airway protection, mechanical ventilation, and intravenous fluids and alimentation can prolong life in patients with severe neurological failure. But these supportive treatments will not restore brain function. It is the right of these patients and their families to choose to refuse life-prolonging treatments that are considered burdensome and without reasonable hope of benefit, but their decisions to do so can be met with requests for a third-party review or a legal challenge (e.g., Nancy Cruzan and Terry Schiavo cases), an outcome that demonstrates society's uncertainty in the face of severe primary brain dysfunction.

For some reason people tend to distinguish brain dysfunction from organ failure that produces severe physiological problems. The central nervous system serves as the basis for our consciousness, awareness of environment and self, and ability to interact with others. Functioning heart and lungs are a necessary but not sufficient condition to permit consciousness and awareness of self. It would seem logical that we would be most energetic in intervening when the heart and lungs fail because these organs support the activities of the primary central nervous system. Yet, when

the brain fails and we permanently lose self-awareness and consciousness, many are inclined to be quite aggressive in continuing interventions because the heart and lungs are still working. This paradox in our thinking has not been systematically explored but may reflect scientific knowledge of the central nervous system that is less well-developed than that of other organ systems and a recognition that brain failure is not “terminal” in the traditional meaning of the word.

The case at hand

Mrs. Henderson is in a persistent vegetative state. She is aware of neither herself nor her surroundings and cannot interact with others. She has sleep-wake cycles, and her eyes spontaneously open. Mrs. Henderson is not conscious and has no higher cortical function. Her movement is reflex-driven and not purposeful; speech is absent; her condition has remained unchanged for at least 7 months and is irreversible.

Dr. Bernard asks Mr. Henderson to consider “goals for his wife’s care.” Although the doctor may be criticized for not bringing this issue up earlier, he does have several motives for asking the question. First, the doctor and the hospital staff need to have a sense of how aggressive to be in the diagnosis and management of other medical problems that may arise. Second, the standard of care for the chronically ill requires that the patient’s clinical and lab reports be shared with the appropriate decision makers at periodic intervals, so options for future care along with its risks and benefits can be discussed. This requires an exploration of the patient’s values and those of the decision makers. Third, the doctor and staff may have a sense of being useless and providing futile care. Despite all of their knowledge and care, Mrs. Henderson’s neurological status is not going to improve, and perhaps their skills can better serve other patients. This consideration is not disrespectful but factual. Hospital resources and staff are not limitless. Patients in a persistent vegetative state can develop complications and comorbidities that consume staff time and energy at other patients’ expense. Lastly, continued care is expensive and may be financially burdensome to both society and family without a corresponding benefit.

Mr. Henderson is conflicted. Although his wife has a living will that could justify discontinuation of the food and fluid, he knows that she would want to be true to the principles of her Catholic faith. And Dr. Bernard is also conflicted. He must practice medicine within the structure of the hospital’s ethical and religious framework but, as a physician, desires to honor his patient’s legitimate wishes as noted in the advance directive.

The resolutions of these conflicts are beyond the expertise of the managing physician and require an ethics consultation. One would expect the ethics consultant to first ascertain the prognosis of the patient (not terminally ill but incurable and without decisional competence). Second, the ethics consultant would review the living will to understand its contents and instructions and to verify that it was properly executed. Third, the ethics consultant would decide whether withdrawal of food and hydration was an ethically acceptable option in the care of Mrs. Henderson. This determination would be based on the *Ethical and Religious Directives for Catholic Health Care*

Services [1]. The ERD, as it is called, is a well-reasoned and carefully written set of principles that guide Catholic health care facilities and policies. All Catholic health care institutions and physicians are required to follow these directives. Lastly, the ethics consultant would make certain that withdrawal of nutrition and hydration from a patient in a persistent vegetative state is not prohibited by state law [2]

The ERD states that a person may “forgo extraordinary or disproportionate means of preserving life. Disproportionate means are those that in the patient’s judgment do not offer a reasonable hope of benefit or entail an excessive burden, or impose excessive expense on the family or the community” [3]. A patient’s advance directive can clearly indicate what his or her position would be if he or she were able to speak. Although we cannot determine the exact reasoning of the patient, the fact that the living will is executed is evidence that the means (artificial hydration and nutrition) are disproportionate. The ERD affirms the right of an individual to have an advance directive, but the institution is not obligated to follow the advance directive if its instructions conflict with Catholic teaching [4].

Does withdrawal of hydration and nutrition from patients in persistent vegetative states conflict with church teaching? The question arose because of a papal allocution in 2004 delivered by Pope John Paul II. The papal statement defined nutrition and hydration as ordinary means needed to provide comfort and seemed to indicate that food and fluid must always be provided. By contrast, the ethical and religious directives state that

...a person has a moral obligation to use ordinary or proportionate means of preserving his or her life. Proportionate means are those that in the judgment of the patient offer a reasonable hope of benefit and do not entail an excessive burden or impose excessive expense on the family or the community [5].

A critique of the papal allocution and the weight to be accorded it is the subject of analysis in another article in this journal issue as well as in other learned treatises [6]. At the present time, the papal statement has not led to a reconsideration of the statements contained in the ERD.

The ethics consultant in this case would find that the patient’s advance directive and her surrogate decision maker indicate that the patient determined that fluid and nutrition would be disproportionate means of maintaining life. Thus, withdrawal of hydration and nutrition would be an ethically acceptable option in her care, provided that state law allows withdrawal.

Keep in mind, however, that ethics consultations are rarely determinative. The consultant simply advises whether proposed care plans are ethically acceptable options. The case we have discussed could easily progress to a situation in which the husband wants to continue hydration and nutrition based on respect for his wife’s faith and the doctor thinks that it is futile and should be discontinued. In this

scenario, since Mrs. Henderson's advance directive was executed before the papal allocution, the ethics consultant could find that continued hydration and nutrition of the patient is an ethically acceptable option of care.

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