

Virtual Mentor

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CASE AND COMMENTARY

The Letter and Spirit of a Directive, Commentary 1

Commentary by Mark G. Kuczewski, PhD

Case

An 83 year-old woman, Mrs. U, was admitted to the hospital from a personal care home due to a stroke with left-sided weakness and aphasia. She had a history of Parkinson's disease, coronary artery disease, and a prior stroke several years ago. The day after admission she was seen by a neurologist who noted dysarthria (ie, problems of speech articulation due to muscular control disturbance) and a severely diminished gag reflex. She was not ambulatory but did respond to right-sided commands. Speech and physical therapy were recommended.

A speech therapist also recommended that Mrs. U not ingest anything by mouth due to her swallowing difficulties. A Dophoff (nasogastric) tube was inserted for feedings. Mrs. U subsequently pulled out the tube twice; the neurologist's notes indicated she would need a peg tube (inserted into the stomach) to survive. At that time, Mrs. U's daughter June, who lived nearby, refused the peg tube but eventually agreed to reinsertion of the nasogastric tube as a temporary measure.

A social worker spoke at length with June, who, wanting to follow the wishes expressed in her mother's advanced directive, was reluctant to agree to any feeding tube at all. Mrs. U's advanced directive, typical of the living will forms used in Pennsylvania, stated she would not want artificial nutrition and hydration if she were in a terminal condition or permanently unconscious. The next day June, still uncertain, was advised to confer with her sister Donna, who lived out of town, in hopes that they would clarify their mother's intent. Mrs. U's family physician also spoke to June, explaining to her that a peg tube was not an "extraordinary measure."

Due to uncertainty about the patient's decision-making capacity, a psychiatrist was consulted. The psychiatrist described the patient as disoriented and lacking insight, with impaired cognition. He deemed her not competent to make decisions at that time. The social worker again talked with June, who had spoken with Donna. The daughters were in agreement in their refusal of any type of tube feeding for their mother.

During the next 2 days, the psychiatrist examined Mrs. U again, finding her mental status to have gradually improved. She appeared to understand what a peg tube was and that it was necessary to provide her nourishment. He declared her capable of decision making at that time.

The hospital's ethics review group, summoned to consider the case, determined that the living will was not applicable at this time because Mrs. U was neither terminally ill nor unconscious and was found competent by the psychiatrist. In light of this, they contacted Mrs. U's daughters and arranged a conference call for the next morning. After receiving the new information, June and Donna differed in their opinions.

In the meantime, the patient was given a barium swallow. It showed that it was still not safe for her to take nutrition orally. Due to the psychiatrist's most recent evaluation of the patient's decision-making capacity, she was referred for a surgical consultation. The patient thought she wanted a peg tube but indicated that she also wanted family agreement. Her daughters were again contacted with this information and presented with Mrs. U's 3 treatment options: (1) placing a Dohoff tube and physical restraints to prevent the patient from removing it, (2) placing a peg tube with no restraints, or (3) transfer to another facility for evaluation and treatment. Shortly thereafter June, who voiced opposition to artificial feeding in the conference call, telephoned the social worker to say she now agreed with her sister on insertion of the peg tube.

The peg tube was inserted the same day. Within a few days, the patient was stable and was transferred to a skilled nursing facility.

Commentary 1

This kind of case raises myriad questions, and there are innumerable points on which one can focus.¹ However, it is all-important to be clear on the general framework and the principles that should guide decision making in such situations. Otherwise, we run the risk of invoking legalisms as a smoke screen for one's own preferences or prejudices.

A competent patient has a virtually unlimited right to refuse treatment. A patient who lacks decision-making capacity, ie, is incompetent, has the same rights as a competent one, but the manner of exercising those rights is, of necessity, different.² Usually these rights must be exercised through a written directive or through family members' attempts to determine what the patient would want if she possessed her decision-making capacities. These general principles must be kept in mind when dealing with such concepts as "ordinary treatment," the integrity of the medical profession, and the nuances of state laws. These concepts and regulations cannot trump a patient's fundamental rights. Rather, they are devices to assist in interpreting and respecting patient wishes.

There seems to have been little doubt in the minds of the health care team members that Mrs. U lacked capacity to make treatment decisions early in the process. Thus, her daughter(s) were appropriately contacted to act as surrogate decision makers. They made their initial assessments of the situation based upon their mother's advance directive. The treatment team did well to explain that the directive could not be applied in a simple deductive manner to the present case. The conditions

specified by the form did not obtain to this case. Nevertheless, the daughters are still ethically entitled to accept or refuse treatment for the patient based on what they believe their mother would or would not have wanted. We ask them what their mother would probably say to us if she could sit up and speak. Certainly, the values that caused their mother to create an advance directive are relevant to this decision-making process even if the directive is not. The health care team seemed to be unhappy with the decision that the daughters arrived at under such specifications. Thus, they directed the attention to a variety of other issues such as legalisms surrounding the living will and questions concerning "ordinary treatment."

It becomes much easier to sympathize with the health care team once Mrs. U appeared to regain partial decision-making capacity. One cannot in good conscience deny life-sustaining treatment to a patient who seems to be consenting to these measures. A presumption in favor of treatment must then govern action. However, good faith requires asking whether the patient is making a decision out of momentary fear, disorientation, or a desire to please the treatment team. That the patient gave some indication that she wanted her daughters' agreement on this decision should give the treatment team pause about their steadfast opposition to the daughters' decisions. The team probably would have done well to bring the patient and family together for a conference on treatment goals and the particular decision at hand. This might have helped further to restore the patient's decision-making capacity.

Understanding the decisions of the treatment team requires separation of motivations and reasoning. In this case the health care team seems to be motivated by a desire to provide treatment to the patient. Like many health care professionals, they find it very difficult to allow a patient to die who is at least semi-conscious. Those involved in the case seem to have a bias in favor of administration of nutrition and hydration, and, once a patient regains some consciousness, they view refusal of this treatment as "starving" the patient. Of course, it is also quite possible that placing this tube may not help the patient at all.³

Health care team members are entitled to their feelings and to some extent, to determinations of their standards of care. They are free to try to persuade the patient and/or her surrogate(s) to choose in accord with the judgments of the team. However, health care professionals have an obligation to be sure that they do not give misinformation or spread misunderstanding in an effort to persuade. This happened in regard to 2 points:

1. Ordinary treatment: Legally speaking, patients have a right to refuse all treatment. It does not matter whether one calls it "ordinary" or "extraordinary." From a legal standpoint, introducing this distinction into the process was a red herring. Ethically speaking, their use of the term was also mistaken. One cannot simply call artificial nutrition and hydration "ordinary." Whether a treatment is ordinary or extraordinary depends on whether it is a measure that is "proportionate" to the case.⁴ That is, does it

bring benefits that outweigh its burdens? In this case, the answer is not obvious. This question is exactly the point at issue between the health care team and the patient's daughters.

2. The Pennsylvania Advance Directive for Health Care Act: Like the advance directive statutes of most states in the US, this law provides immunity from liability to physicians who make a good faith effort to follow a patient's living will under specified conditions. Contrary to the inferences of the treatment team, such a law does not compel treatment under all conditions other than those it specifies.^{5,6}

References

1. Case adapted with permission from Kuczewski M, Pinkus RL. *An Ethics Casebook for Hospitals: Practical Approaches to Everyday Cases*. Georgetown University Press; 1999.
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