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A Physician's Ethical Duty When Confronted by Unreasonable Expectations and Legal Threat

ALYSON E. DOBRACKI, D.O.

DobrackiA@mlhs.org

Internal Medicine, Main Line Health, Philadelphia and Western Suburbs, Pennsylvania, U.S.A.

*Address correspondence to: Alyson E. Dobracki, D.O., Internal Medicine, Main Line Health, Philadelphia and Western Suburbs, Pennsylvania, U.S.A. E-mail: DobrackiA@mlhs.org

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ALYSON E. DOBRACKI, D.O.

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Internal Medicine, Main Line Health, Philadelphia and Western Suburbs, Pennsylvania, U.S.A.

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A 97-year-old gentleman with cognitive impairment, but not in advanced dementia, was admitted to the hospital with a diagnosis of aspiration pneumonia after a month-long deterioration of his health following the death of his wife of nearly 80 years. He and his family were well-to-do, and his several children were lawyers. During his long hospital course, he suffered from delirium and was only intermittently able, and progressively less able, to make his own medical decisions.

The patient, George (name changed), in his advanced age and debilitated condition, continued to decline. He was in and out of the intensive care unit, barely avoiding intubation and mechanical ventilation. He continued to have aspiration episodes, resulting in recurrent pneumonia requiring four separate courses of antibiotics in his 3-month hospital stay. He also intermittently required bipap, a tight mask that forcefully blows air to support respirations.

During the protracted hospital course, George was prescribed speech therapy, in an attempt to retrain and strengthen his swallowing muscles. Conversations took place regarding considering "comfort-directed care," but George's family adamantly wanted him to reach 100 years old. After much delay, his family brought in George's living will, which indicated that he would not want a feeding tube and would not want to be placed on life support, and the family agreed to honor his wish while showing their strong desire that George would live up to 100 years.

George continued to aspirate, and the decision was made to make him N.P.O. (nothing by mouth allowed). His family demanded that he be fed intravenously, which is not a recommended therapy for a person who has a working gut. If artificial feedings are pursued in a case like this, the standard of care dictates that it should be done via tube (either through the nose or placed directly into the stomach). There are many risks of infusing nutrients directly into the bloodstream: severe infections, pancreatitis, electrolyte abnormalities, and more. However, some of us, practitioners, ordered the intravenous nutrition, likely because of a threat made by his lawyer children.

The risks of the parenteral nutrition far exceeded any expected long-term benefits, and the withholding of oral food and water was distressing to George, who did not understand the reasoning behind his N.P.O. status. George continued to decline mentally and physically. With his nothing-by-mouth status, he called out for "water! water!" When he intermittently required the bipap, he would pull off the mask and require mitts on his hands as a type of restraint. He became uncooperative and aggressive with the speech therapist. He stayed in bed all day and needed to be turned in the bed frequently in order to prevent skin wounds. He refused and hit the staff when turns were attempted, and he developed a wound on his foot as well. He required frequent blood draws to test his electrolytes while on the intravenous nutrition, and he would swat at the technician each time. He became anemic due to the blood draws. The protein delivered directly to his blood stream broke down into nitrogen products that led to confusion, so the much-needed protein for wound healing had to be decreased. He yelled at us, "You are torturing me. I want to die. Please." Nurses, physicians, and therapists were all in emotional and ethical turmoil caring for this patient. However, all the while, his

family continued to want him to live until he was 100. Any time any changes were made, or if there was a suggestion of comfort care, his family would make litigious threats.

We, caregivers, struggled with honoring George's surrogate autonomy stemming from the family's unreasonable wishes. As the autonomy of a formerly competent patient like George's is interpreted as "self-ruling," the condition of which requires the patient's competent will, free of coercion; his surrogate autonomy should be a "substituted judgment" which accurately reflects George's wishes, preferences, and values.¹ However, this case was complicated for two reasons. First, Pennsylvania law does not permit the living will to be honored unless the patient is in end-stage, but George was not in end-stage yet. Second, George already lost his legal competency, the fact of which placed himself at the mercy of his healthcare proxy, his family. But it seemed that the family was not exercising the substituted judgment on behalf of George. The family set a clear goal to keep him alive until he was 100 years old.

As we read George's living will, it clearly stated that he did not want his life to be prolonged to the greatest extent possible, that he did not want life sustaining or prolonging treatments to be used if he has no reasonable hope of long term recovery, and that he did not want treatments if the burdens of said treatment outweighed the expected benefits. This made us feel that the modalities we were prescribing were violating our ethical duty to respect George's autonomy. And it seemed as if his family, too, was violating their ethical duty by their failed substituted judgment.

The family's exercise of the surrogate autonomy seemed to be based on their thought that helping their father to live longer would be a beneficent act to do. However, even if we concede to the family's assessment of the care plan, were their decisions made in an ethical context? I would suggest the answer to this question is a resounding "no." Though George was not competent, it was clear, we all felt, that he perceived harm being forced upon him, rather than any good.

I wonder what we would have done, if George had been competent and had requested, himself, for these futile, life-prolonging measures. I would have made a great effort to convey accurate information about his condition to him and recommended that the active treatments should not be provided, so as not to violate, but to honor his autonomy. I find the American Medical Association state, "Physicians are not required to offer or to provide interventions that, in their best medical judgment, cannot reasonably be expected to yield the intended clinical benefit."² I also find that the European Society for Clinical Nutrition and Metabolism's guidelines speak in the same line of thought: "autonomy does not mean that a patient has the right to obtain every treatment he requests . . . artificial nutrition is used in accordance with a realistic goal of individual treatment . . . treatments which are futile and do only prolong the suffering . . . have to be avoided."³

However, George's case was more than continuing futile medical treatment. We felt our commitment to non-maleficent duty to him to be compromised. Those life-prolonging measures the family was requesting were at the expense of forsaking our vow to "Do No Harm" as doctors. At age 97, in a man who is begging for "water!" and screaming that we were torturing him, it felt clear that we were harming him. However, what made us feel so lost and helpless was the threat of a lawsuit. We tried to establish rapport and understanding of the family. Meanwhile, we were reminded that they were lawyers – a not so subtle threat of litigation if we did not comply with their demands – and that their goal was for him to live to 100 years old.

What happened with George then? The case went to the Ethics Committee. Though physicians all spoke of the case being futile, we finally got a second courageous physician to document that assessment. We presented to the family that the prescribed modalities were futile and that many of these modalities, including parenteral nutrition, would not be reordered. We gave them ample time to find an alternative facility to provide the care modalities that they desired, and with their connections in the medical community, they found another facility, and George was ultimately transferred. We understand that he ultimately was placed on mechanical ventilation and underwent feeding tube placement. These modalities were in obscene and expressed disregard to his documented wishes in his advanced directive. We found his obituary in the newspaper only a few weeks after transfer. Due to the constraints of this forum and the need for patient privacy, not all the details or circumstances could be completely revealed. However, this case, and many others relating to nutrition at the end of life, are some of the most difficult that we will encounter in our careers.

ACKNOWLEDGEMENT

¹ Jim Summers, "Principles of Healthcare Ethics," in Eileen Morrison and Beth Furlong, eds., *Health Care Ethics Critical Issues For the 21st Century* (Burlington, MA: 2014, Jones & Bartlett), 49-50.

² American Medical Association, "AMA Code of Medical Ethics," accessed, March 22, 2017, <https://www.ama-assn.org/delivering-care/ama-code-medical-ethics>.

³ Wilfred Druml, Frank Oehmichen, Alan Shenkin, Pierre Singer, Peter Soeters, Arved Weimann, and Stephan Bischoff, "ESPEN Guideline on Ethical Aspects of Artificial Nutrition and Hydration," *Clinical Nutrition* (2016) 35 (3): 546-7.

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