CLINICAL VIGNETTE

When Goals of Care Discussions Get Messy

Manuel A. Eskildsen, M.D., MPH, and Patricia Harris, M.D., MS

Case

A 79-year-old white male retired college professor was hospitalized in June 2014 after he sustained a fall. During the admission evaluation, he reported that he had been diagnosed with Parkinson's disease approximately two years previously with a possible diagnosis of Lewy Body dementia. His only other medical conditions were well-controlled hypertension and benign prostatic hyperplasia. His major symptoms were frequent falls and tremors, but he also noted some word finding problems, daytime somnolence, and hallucinations. His medications at the time included carbidopa/levodopa, amlodipine, enalapril, donepezil, finasteride, aspirin, and multiple vitamins.

His score on the Montreal Cognitive Assessment evaluation was 6/30 with marked apraxia and 0/5 recall. He was not oriented to time or location. Exam demonstrated bilateral apraxia and bilateral action tremor with normal gait. Subsequent imaging by positron emission tomography (PET) of the brain injected with 18-fluoro-2-deoxyglucose (FDG) demonstrated findings consistent with a progressive neurodegenerative disorder such as Lewy body disease.

He is married and lived with his wife at the time of the initial hospitalization. He has two daughters and several grandchildren. He is a retired language professor. He has a durable power of attorney (DPOA) and has named the older of his two daughters as the primary decision maker. His living will explicitly states that he did not desire any life-prolonging measures if he were both mentally and physically incapacitated, had a terminal, end-stage condition, or if he were in a persistent vegetative state.

The patient and his wife decided not to return to their home and moved in with their daughter. Carbidopa-levodopa was discontinued with subsequent resolution of hallucinations.

During routine clinic visits, the primary physician addressed goals of care with the patient's wife. She demonstrated an unwillingness to make such decisions. The patient's older daughter, who did not attend any clinic visits, completed and signed a Physician's Order for Life Sustaining Treatment (POLST) that requested full resuscitation, intubation, and a trial of artificial feeding. The patient was unable to participate in these conversations and would not respond when asked questions regarding goals of care.

Over the next two years, the patient's illness progressed. He became less verbal, his walking ability diminished, and he began to aspirate liquids, solids, and oral secretions. Family had been giving him thin liquids in his diet, despite recommendations to thicken all liquids. Two years after his initial presentation, he developed an aspiration pneumonia requiring hospitalization.

The patient was found to have severe dysphagia by a modified barium swallow study. He also lost 20 kg (44 lb.) over a year. His family requested that a gastrostomy feeding tube be placed.

Given the patient's written directives and the medical team's opinion that the patient had an end-stage condition, the team convened a goals of care discussion with the patient's wife and two daughters. His wife and two daughters were adamant that he be fed artificially, stating that he did not understand what he signed in 2012 that "we can't give up on him" and "he would do this for us if the tables were turned."

The medical team, uncomfortable with pursuing artificial feeding, asked for assistance from the ethics committee at the hospital. The recommendation from the ethics committee was that because there was a conflict between the first advance directive signed by the patient and the POLST signed by the daughter that the team seek advice from hospital legal counsel. Legal counsel ultimately recommended to the team that because his family members stated that they were using substituted judgment (making the decision that the patient would have made under similar circumstances) that they deferred to the medical team about a decision on feeding tube placement. After considerable discussion, the team decided to pursue placement of the tube, and the interventional radiologist agreed to place it.

Three months later, the patient is still alive. He is bedbound, feeding-tube dependent, nonverbal, and has a large stage IV pressure ulcer. He has not been weighed.

Discussion

Advance directives are written documents that are designed to allow competent patients the opportunity to guide future health decisions, should their decision-making become impaired. These documents deal with a choice of surrogate decision makers, their preferences for life-sustaining treatment, or both. The Institute of Medicine, in a 2014 report, found that the U.S. healthcare system is increasingly burdened by factors that hamper delivery of quality end-of-life care, and identified advance care planning as a critically important element to good care for patients with advanced illness.[1] In 2015, the Centers for

Medicare and Medicaid Services issued a proposed rule establishing payments for advance care planning discussions with Medicare beneficiaries, which would reimburse providers for time spent discussing advance directives.[2]

There are two types of advance directives: instructive and proxy. Instructive directives are represented by the living will. A living will is a written instruction for a physician as to how to use or not use specific life-sustaining treatments when the person no longer has the capacity to make health decisions. Proxy directives have different names, but for this document we will use the term **durable power of attorney for healthcare (DPA-HC)**. This document designates another person to make health decisions when the patient is unable to make health decisions for themselves. Each type of advance directive has benefits and drawbacks. While a living will allow an individual a way of making their end-of-life preferences known, no document can contemplate every eventuality that may occur when an individual is close to death, and thus, a living will, however detailed, may not provide enough guidance. A DPA-HC fills in some of the gaps, by allowing a person who knows the patient well to adapt the preferences stated in the living will to specific life situations. However, the proxy may not always keep the patient's preferences in mind when making health decisions.

In the United States, the 1991 Patient Self-Determination Act was the first federal law specifically addressing advance care planning. It requires that patients be informed about the right to participate in their own healthcare decisions, including the development of advance directives.[3] State laws vary with regards to advance care planning. While all states offer a way for patients to document advance directives in a legally binding way in some form, the documents used and the terminologies are often different. States also vary in another key respect. States laws create a list of default surrogates, starting with a spouse, and then a next-of-kin, which would apply in case there are no documented advance directives. This is especially relevant for LGBT patients, whose chosen surrogates may not be a family member, and thus may have a default decision maker not of their choice forced on them if there are no advance directives.

California law allows for an Advance Healthcare Directive Form, which permits a person to designate a healthcare agent, and importantly, for mechanisms to restrict that agent's authority in specific situations of the person's choosing. This form also allows for statements of end-of –life preferences for life-sustaining measures.[4]

A living will and a DPA-HC may come in conflict, like they did in the case discussed above. Because a living will can't contemplate every specific eventuality, and a DPA-HC has the legal authority to make decisions if a patient is judged to be incapacitated, most often the decision of the DPA-HC will take legal precedence.

However, what's legal may not always be the most ethical approach. One possible framework for helping families and patients make decisions in difficult end-of-life situations may be as follows. First, the medical appropriateness of the patient request must be assessed by the medical team. If the expected benefit of the surrogate's request is outweighed by the harm, then it would be appropriate for the medical team to decline the request. Second: is the surrogate's substituted judgment a plausible interpretation of a patient's wishes? Obtaining as much information as possible about patients' wishes from different sources may help meet this standard. And third: did the patient understand the purpose and nature of the LW, and that a DPA-HC could override the living will?[5]

Conclusion

In our case, his family made a request for a feeding tube placement that appeared to be in conflict with his living will. Even though the medical appropriateness was in question due to the lack of evidence for survival benefits for feeding tubes in patients with advanced dementia, there was no proof that the intervention itself was medically harmful, and the family gave evidence that the patient would have wanted a feeding tube in this situation, despite what he signed in his advance directive. Thus, the team elected to have the feeding tube placed.

REFERENCES

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