

Medical Ethics



By Jonathan Evans, MD, MPH, CMD

When People Take Matters Into Their Own Hands

The Case

A 78-year-old man with a 4-year history of recurrent non-small cell lung cancer, metastatic to the brain, was admitted 3 weeks ago to a skilled nursing facility for end-of-life care. He had been receiving hospice care at home for 2 months, following a prolonged hospitalization for chemotherapy and brain radiation that was complicated by sepsis. He continued to receive hospice care at the nursing facility. The patient had a history of atrial fibrillation with complete heart block (status post-AV nodal ablation) resulting in placement of a permanent cardiac pacemaker 5 years ago.

Four years ago, the patient executed a written advance directive, in which he indicated that in the event that his condition was terminal, he did not wish to be kept alive by artificial means. He named his son-in-law, a cardiac-device technician, his power of attorney for medical decisions in the event that he lost the ability to make and communicate them for himself. He chose his son-in-law because they were close and because he was the only person in the family involved in health care and therefore, the patient reasoned, had extra knowledge about medical issues.

Soon after the patient enrolled in hospice, his son-in-law inquired of the hospice nurse about having the pacemaker turned off. Hospice staff contacted the cardiologist who had placed the device. The cardiologist refused to turn the device off as the patient was completely pacemaker-dependent and doing so would result almost immediately in death, which the cardiologist reasoned would be equivalent to murder. Moreover, the cardiologist indicated he did not want anyone to die in his office.

At the time of admission to the nursing facility, the patient appeared comfortable but quite ill. He appeared extremely frail, cachectic, and weak. He weighed 120 pounds while being approximately 6 feet tall. He was unable to stand, even with the assistance of another person. He required supplemental oxygen to breathe comfortably. His pain was well controlled with opioids and corticosteroids.

Over the next 3 weeks, the patient became completely bedbound. His oral intake and urine output decreased. He slept most of the time. Ultimately, he stopped eating altogether. He became unresponsive. For the next 30 hours, the family kept a constant vigil at his bedside. Finally, the son-in-law encouraged the patient's wife, daughter, and grandchildren to leave for dinner. He

agreed to remain behind in the patient's room in case anything happened.

Twenty minutes later, while making her routine rounds, a facility nurse entered the patient's room and observed the son-in-law sitting on the bed next to the patient. There was a four-inch doughnut-shaped magnet with the name of a prominent cardiac device manufacturer on it, sitting on the patient's chest. The patient was dead. The son-in-law indicated that he had turned off the patient's pacemaker using the magnet.

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The nurse called her supervisor who pronounced the patient dead. The body was removed to a funeral home. Later, after a discussion between the nursing director and the facility administrator, facility leadership felt that it was their duty under the Elder Justice Act to call the police. When the police arrived, they were upset and accusatory toward facility staff because they had altered the possible crime scene.

Discussion

To some, this case might be a simple example of the withdrawal of life-sustaining treatment from a patient who had previously expressed his desire not to be kept alive by artificial means. The right to refuse or discontinue treatment has been affirmed as a constitutional right by the U.S. Supreme Court, is codified under federal law (the Patient Self-Determination Act), and is generally considered an ethical choice based upon the principle of autonomy. Furthermore, ethicists consider discontinuing treatment to be morally equivalent to not starting treatment.

Discontinuation of life-sustaining treatment by medical personnel in health care settings is commonplace today. Discontinuation by family members in health care settings is not, however. Or at least it is not commonly acknowledged.

Moreover, despite an explicit advance directive, the manner in which the son-in-law took matters into his own hands—turning off the pacemaker when no one,

including the patient's wife, was looking—feels wrong somehow. It's not the way we do things in health care, and we like doing things certain ways (though not necessarily for our patient's or a family's sake). We naturally question the son-in-law's motives.

What he did feels wrong not so much because of the outcome (although withdrawing treatment often feels worse than not starting treatment) but because of how it was achieved: in secret, without asking permission, without a doctor's order, and without the involvement of others who are supposed to be "in charge."

Autonomy, Power, and Control

In the United States over the past few decades, autonomy—the right to make decisions on your own behalf and to choose surrogates to carry out your wishes—has reigned supreme among all other ethical principles. This right to self-determination has come to be seen as almost synonymous with American. Nevertheless, society often puts strict limits on autonomy. Moreover, autonomy, as I have written many times before, is meaningless without power.

While living in the United States may symbolize autonomy, receiving American health care at the end of one's life often epitomizes powerlessness and loss of control, so much so that it has spawned several revolutions—the hospice movement of the 1970s and 1980s and, more recently, the culture change and person-centered care movements—whose goals are to empower patient and family choice.

Much has been written about advance directives being ignored or overruled by medical personnel. Often, patients and families don't get to choose, despite their right to do so. In this case, the cardiologist who inserted the pacemaker refused (largely on ethical grounds) to deactivate it. Had he done so, the patient would have died as a direct result, not because of an underlying cardiac disease, but because the cardiologist had destroyed the electrical system of the patient's heart 5 years earlier, making the patient completely dependent on the pacemaker ever since. In this case, the cardiologist's values and interests trumped those of the patient or his surrogate.

The cardiologist's response in this case was not at all unusual. Moreover, turning off a pacemaker or an implanted defibrillator requires proprietary equipment that even many physicians, including most in primary care, do not have access to. So only the cardiologist gets to decide. What was most unusual about

this case was that the surrogate had the unique knowledge, tools, and therefore power to carry out his choice and, ostensibly, the patient's.

If only cardiologists can withdraw treatment in the form of a pacemaker, defibrillator, or other cardiac device, should they, as a condition of being paid to insert the device, be required to remove or deactivate it if the patient so chooses? Should this be a matter of ethics or law?

"Pulling the Plug"

When life-sustaining treatment is discontinued, families are often present at the bedside by choice. Ironically, physicians who write the order that life-sustaining treatment be discontinued usually are not present, likewise by choice. It is typically a nurse (or a respiratory therapist in the case of a patient on a ventilator) who physically withdraws the treatment. In fact, even though withdrawing treatment is commonplace in every hospital, many physicians now complete their training without ever actually seeing a patient die.

Should physicians who order an end to life-sustaining treatment be discontinued be required to discontinue it themselves or at least be present at the time? How far does a practitioner's ethical obligation extend, beyond merely acceding to a patient or surrogate's wishes? What about the practitioner's right to refuse? Does a physician even have such a right if there is no one else to transfer care to?

Is discontinuing treatment the exclusive purview of medical professionals? Although refusing or withdrawing treatment is considered a fundamental patient right, the power to do so often lies only with physicians and other practitioners. We have an ethical obligation to empower patients and their surrogates to get their wish.

The interests of the patient should almost always supersede our own. As culture change progresses, patients and families will be more empowered in the future, as they should be. The result may be increasingly uncomfortable for many health care providers, however, when our own feelings and interests are at odds with our patient's.

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