Virtual Mentor

American Medical Association Journal of Ethics February 2007, Volume 9, Number 2: 91-98.

Clinical case Turning off an implanted life-saving device Commentaries by Lofty L. Basta, MD, and Katrina A. Bramstedt, PhD

Mr. Stone had been experiencing cardiac problems, ranging from chronic hypertension to cardiomyopathy, for about 10 years when he was diagnosed with heart failure and was told that he would need a heart transplant. With a heart not forthcoming in the near future, Mr. Stone's long-time cardiologist, Dr. Holmes, suggested the possibility of inserting a left-ventricular assist device (LVAD) as a bridging strategy while they waited for a suitable donor to become available. Mr. Stone readily agreed to the idea. At 53 and a mechanic by trade, he told Dr. Holmes that he would do anything to relieve the burden he was currently placing on his wife by being unable to work and asked that the LVAD implantation be done as soon as possible. Dr. Holmes asked Mr. Stone if he had changed his advanced directives since his last surgery: "No doc, I still got the DNR order in there. I don't want to be a burden if it comes to that." Satisfied, Dr. Holmes called the hospital and scheduled the surgery.

On the appointed day, Mr. Stone arrived at the hospital for the surgery, his wife, Martha, at his side. As he was being wheeled to the operating theatre, Mr. Stone gave his wife a quick peck on the cheek: "Don't worry, dear. I'll be back in a jiffy. Dr. Holmes will look after me." The operation itself appeared to be another routine procedure for Dr. Holmes. After closing up the last skin wound, he checked Mr. Stone's cardiac function. On finding that it had improved as expected, he went off to scrub down, leaving his nurse aide, Mary, to take Mr. Stone to the recovery room. As he was washing his arms, Mary rushed in.

"Dr. Holmes, Mr. Stone just had a seizure."

"Call neurology, Mary. I'll be there right away."

Anti-convulsant treatment stabilized Mr. Stone's condition and he was kept in the intensive care unit. Although he regained consciousness a few days after the surgery, Mr. Stone developed complications with pneumonia and was placed on a mechanical ventilator, forcing him to stay in the ICU.

The pneumonia failed to resolve in the following weeks. On consultation with the respiratory service, Dr. Holmes discovered that Mr. Stone's lung parenchyma had been irreversibly damaged and it looked like his condition would not improve much.

This was bad news; as a member of the hospital transplant committee, he knew very well that this would make Mr. Stone ineligible for a heart transplant.

Entering Mr. Stone's room, Dr. Holmes moved up close to the bed so that Mr. Stone could hear him better. "Mr. Stone, I am afraid that there are some complications to your case." Mr. Stone listened, and, apart from a few labored breaths on the ventilator as Dr. Holmes mentioned his loss of eligibility, he remained unemotional.

After Dr. Holmes finished, Mr. Stone shifted, and, motioning Dr. Holmes up close so he could whisper to him, Mr. Stone breathed: "You and I both know I'll be stuck like this for the rest of my life. I don't want to. This will blow our savings and I want Martha to get on with her life. Can you turn off the machine in my chest and let me be?"

Commentary 1

by Lofty L. Basta, MD

Death is a natural event. Every life on earth will have a beginning and an end. Thanks to astounding advances in medicine during the past half-century, health has improved for many. For some, the moment of death can be postponed by technological interventions, but the interventions may not bring back independence or former quality of life. Unfortunately, death has been transformed into a blameseeking pathology. When someone dies there must be a mistake by an offender.

This mind-set is propagated among the lay public as well as among physicians and is fueled both by our health care system, which rewards the use of more interventions [1], and by our legal system, which punishes physicians who dare to do less than the latest tests—although fear of such reprisals tends to be greatly exaggerated. The inevitable result is that many dying people undergo procedures that they would not have chosen had the procedures and their ramifications been explained clearly—and understood—allowing them to make rational decisions [2].

The foregoing case does not present a true ethical dilemma; the patient had advanced heart disease that could not be improved by medication. After careful discussion with Dr. Holmes, Mr. Stone agreed to have a LVAD inserted as a bridge to a cardiac transplant. He was placed on the ventilator because of a postoperative irreversible lung disease that rendered him ineligible for a heart transplant. The fact that the patient was only 53 years old made an imminent death more tragic but did not alter the medical facts. He asked for his LVAD to be stopped and he wanted to discontinue all efforts to keep him alive by technical means [3].

The implanting of devices in terminally ill cardiac patients has proliferated enormously over the past 10 years to the extent that the majority of dying cardiac patients receive one or more devices before saying their final goodbyes [4]. This habit derives from a couple of sources: physicians' applying recommendations from studies to patients who may or may not be similar to the patients in the study and, secondly, from patients' own preferences. Less influential in the clinical decision making are complications and failure rates of these devices and whether they interfere with the natural process of dying. It is as though inserting such devices in the dying has become the rite of passage before the death of a cardiac patient [5].

Informed refusal of treatment

Usually, left ventricular assist devices are employed as a bridge to heart transplant [6]. It follows that they should be discontinued once one is no longer a candidate for transplant. Unfortunately the decision is not that easy; recent research suggests that a significant number of patients with advanced cardiomyopathy show a reduction in heart size and improvement in left ventricular function after receiving these devices [7]. This recent data must be shared with the patient and a recommendation made about whether to keep the device for a certain period of time before discontinuation. Of course the ultimate decision will depend upon the nature of the original consent and upon a sincere discussion with the patient about the recent clinical findings. It must be emphasized that the decision either to persist with a treatment or discontinue it and bear the consequences rests with the patient; this is the doctrine of informed refusal of treatment. It is particularly applicable if the initial consent was for transient use of the device [8].

Physicians often are tempted to accept treatment burdens on behalf of their vulnerable patients and to act paternalistically, as if "the doctor knows best." This is wrong; the impulse must be resisted at all times. It is the sacred duty of the treating physician to fulfill the patient's expressed wishes [9]. Doctors have to learn to see through their patients' eyes [10] and understand that they are fellow human beings whose wishes must be honored and obeyed so long as they are not making irrational decisions prompted by dementia, pharmacologically altered mental states, depression or feelings of being unwanted.

Furthermore, advance care planning should be instigated by the primary care physician [11] and should address conditions of irreversibility when death is near and unavoidable. These conditions can be associated with states of unawareness, such as deep coma, advanced dementia or permanent vegetative state [12], dependence on machines, or eligibility for hospice care. The decision makers must determine when and how to use or withhold cardiopulmonary resuscitation (CPR), life-sustaining machines, antibiotics and blood substitutes, and artificial feeding and hydration [13].

Documents that outline the use or nonuse of life-sustaining treatment are widely available. One such document has been developed by Project GRACE and is available at no cost [14]. The patient can indicate decisions about specific interventions on the document after learning more about each procedure and the risks and benefits associated with its use. To leave these weighty decisions in the hands of lawyers or other parties who speak in vague legal jargon about the heroic, terminal and irreversible ignores the patient's right to make his own choices. As an example, patients with advanced but not terminal dementia who had complicating, but potentially reversible, pneumonia—patients who stated that they wanted to die peacefully—ended up receiving aggressive treatment despite having signed such a legal document [15].

To let a person die by allowing nature to take its course is legally, morally and ethically right and, in the case under discussion, desirable. By contrast, to prolong a patient's suffering despite his request is morally and ethically reprehensible and should not be condoned [16]. For Mr. Stone, the left ventricular assist device and the ventilator only postpone his moment of dying; the intervention was initiated in the hope that he would recover lung function. The ventilator failed to achieve its desired effect, so Mr. Stone can no longer be a candidate for a heart transplant, and the treatment should be discontinued. Understandably, it is easier on the treating physician and the family not to initiate a certain treatment than to withdraw it, especially in this case where the device is implanted inside the body. Ethically, however, there is no difference between the acts of withholding and discontinuing life-sustaining treatment when a competent patient has requested it [17, 18].

Medicine was meant to be a loving, caring and compassionate profession [19]. It upholds the primacy of the patient's own wishes. The basic principles of medical ethics remain those of beneficence, nonmaleficence and justice. Beneficence means that the physicians have an obligation to further their patients' interests and welfare. Nonmaleficence dictates that they do no harm and minimize risks to their patients. Justice implies that there is fairness in distributing access to care and services across all patients without discrimination.

Where is nonmaleficence when, through modern medicine, we enslave an unwilling patient while we intervene aggressively in a terminal, irreversible condition? We render an otherwise peaceful death harsh. We may even be denying a spouse a decent life or a grandchild the opportunity to go to college by persisting with a futile, expensive medical intervention [20]. To die on somebody else's terms when you have clearly stated your choices is an unfortunate consequence of modern medicine [21].

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Commentary 2

by Katrina A. Bramstedt, PhD

End-of-life situations are rarely easy due to the emotional bonds between patients and families. Medical technology that prolongs life without cure or relief of suffering further complicates these difficult situations. Today, there are many life-saving medical devices such as implantable cardioverter defibrillators, pacemakers, ventricular assist devices and even a totally artificial replacement heart. These technologies bring the potential for additional ethical dilemmas at the end of life because they have the ability to keep the body alive in futile clinical situations (e.g., multiple organ system failure with sepsis).

Knowing a patient's values and preferences for health care is critical to medical decision making. When patients are alert and manifest the functional capacity to make their own decisions, they can cogently express their thoughts and desires. At the end of life, however, few patients maintain their decision-making capacity; they are often heavily sedated, encephalopathic or even comatose. In such cases, it is impossible to converse with patients to understand their wishes, so the medical team must turn to family, friends or prior known expressions of the patient's values. In these situations, medical personnel and surrogate decision makers can be assisted by the presence of the patient's advance directive (also known as a living will) [1].

A living will is a document created by adults at a time when they have decisionmaking capacity. These documents do not have to be drafted by an attorney, and in most states they do not have to be notarized. Their content expresses the person's wishes with regard to life-saving therapies such as cardiopulmonary resuscitation, ventilatory support, artificial feeding and hydration, and dialysis. Some living will template forms allow patients to note with a checkmark which therapies they want at the end of life (e.g., when terminally ill or permanently unconscious), and other forms allow individuals to insert text that specifies their values and wishes.

An alternate form of having one's wishes followed when one has lost decisionmaking capacity is the durable power of attorney for health care (DPAHC). On this form, adults appoint another adult to make their medical decisions when they lose the ability to do so themselves. Often the surrogate decision maker is a spouse, sibling or child, but a friend or clergy member can also serve in this role. Alternate surrogates can and should be named on the form in case the primary surrogate cannot be located, has died, or is otherwise unwilling or unable to function as decision maker. When living will and DPAHC forms are completed, a copy of each should be given to the individual's primary care physician, and one should be placed in the medical chart if the patient is hospitalized. Adults should have formal discussions with their surrogates about the contents of their living wills and be sure that the surrogates have copies of the documents.

Timely discussions with patient and family

In the case described, a ventricular assist device was implanted without a *detailed* prior discussion of the patient's health care values. While Mr. Stone informed Dr. Holmes that his advance directive specified no cardiopulmonary resuscitation be performed, there was no discussion between the two about the significance of the ventricular assist device in making the patient pump-dependent. In this way, the assist device would essentially provide constant cardiac life support, even in situations of clinical futility, unless it was turned off (deactivated) [2]. Such a concept can be psychologically stressful, thus the time for these discussions is before implantation, rather than afterward during critical clinical situations when families are stressed, emotions are strained and patients are often without the ability to make their own medical decisions.

At the Cleveland Clinic, it is standard practice for all patients who are being considered for destination ventricular assist device therapy (permanent implantation) to be evaluated by a social worker and an ethicist who ascertain the patient's current level of decision-making capacity and his or her understanding of the device and its function, the risks and benefits of the implant procedure, and the concept of pump dependence. All patients are also strongly advised to complete living wills and to appoint surrogate decision makers. For those who decide not to complete a living will, expressions of their values are documented in the medical chart for future reference.

At the end of life, when it is clinically and ethically appropriate to turn off medical devices such as ventilators and feeding pumps, the medical team must not forget other concurrent technologies, even if they are implanted in the patient. As an example, powerful shocks from an implantable cardioverter defibrillator at the end of life are not only burdensome, they can prolong the dying process [3]. Ventricular assist devices can keep patients alive almost indefinitely, while their bodies try to shut down and die. Turning off these devices is not a form of euthanasia because doing so allows the patient's disease process to progress naturally until it causes death. Nonetheless, facing these deliberations at the end of life without any prior discussion and contemplation can be very difficult for all involved.

In the case described, Mr. Stone's request for deactivation of his LVAD can be troubling for the medical team and family [4]. A clinician or ethicist should assess Mr. Stone's level of decision-making capacity and verify whether or not he understands his clinical situation and the implications of turning off the device (as well as keeping it on). Mr. Stone should be asked about the content of his advance directive in light of his clinical status and prognosis. Ideally, this discussion should occur first without family present, then with family at the bedside. All patient requests for device deactivation should be thoroughly documented in the medical chart, as should consultations with the medical team. In all situations, the wishes of a patient who has decision-making capacity should be honored. When patients lack this capacity, prior expressions of their health care values and preferences can be used by surrogates for decision making. If a patient's values and preferences are

unknown, decision making should proceed on a best-interest basis that reflects on the patient's clinical status (including coexisting technology burdens and benefits) and prognosis [5].

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