case study

"Doctor, Will You Turn Off My LVAD?"

Mr. P is a 62-year-old man with an extensive history of heart disease and severe heart failure. He underwent coronary bypass surgery ten years ago and has had two heart attacks in the past five years. His quality of life has been deteriorating due to his increasing inability to independently perform many daily activities. He currently lives with his wife and daughter.

Eight months ago, as a result of severely debilitating stage IV heart failure, doctors implanted a Left Ventricular Assist Device into Mr. P's chest as so-called destination therapy. The LVAD helps the heart to maximize the volume of blood it pumps into the body. However, many of the device's controls, as well as its power source (a rechargeable battery), are outside the patient and connected to the pump by tubes and wires that pass through the patient's abdominal wall. Originally used only as a "bridge" to support hospital-bound patients for whom a heart transplant was both urgent and imminent, LVADs are now also used as destination therapy for patients who are ineligible for a transplant. In such cases, patients are sent home with LVADs, which are considered the final stage of treatment for their heart failure.

Mr. P's doctors had told him that the LVAD would improve his capacity for self-care and allow him to lead a more active life. However, his health after its implantation was compromised by chronic wound infections, sepsis, and renal failure. He spent the first five months following the implantation in the hospital; during much of this time, he was in the intensive care unit. He eventually returned to his home but has continued to grow weaker. He now sleeps a great deal, eats poorly, walks little, and needs help to go to the bathroom. He also complains of significant pain.

After three months at home, Mr. P has asked to be readmitted to the hospital so that doctors can disable his LVAD. He understands that he will likely die within hours after the device is turned off, but he no longer wishes to live in his current state. In particular, he cites the indignity of being helped to the toilet and his continuing debilitating fatigue as reasons for his request.

Should Mr. P's physicians accede to his request and disable his LVAD?

commentary

by Jeremy R. Simon

Although LVADs originally supported patients only for a brief time before they received heart transplants, implantation of the devices has recently evolved into a definitive destination treatment for severe heart failure. Therefore, their use is no longer restricted by the supply of transplantable hearts. This use of destination LVADs will become even more frequent now that Medicare covers the cost of their implantation and maintenance. However, Mr. P is the harbinger not just of future LVAD patients, but of a much larger group we will undoubtedly soon encounter—those who have implanted artificial organs essential to their survival. Although LVADs are neither fully implantable nor a full replacement for a heart, they share many ethically relevant features with true artificial organs. These features would make me reluctant to accede to Mr. P's request.

It is tempting to equate Mr. P's situation to requests for removal of life support—cases where respect for autonomy mandates accommodating the patient. However, these cases differ from Mr. P's in several ways. Most importantly, destination LVADs are implanted into patients and, once implanted, can perform their functions independently of hospital-based equipment or even medical intervention. They are meant for patients to live with at home. Once the patient leaves the hospital, the LVAD ceases to be a medical treatment and becomes effectively part of the patient himself, much like a transplanted organ or even a native one. The fact that the LVAD is manufactured and partially external is less important than the fact that it forms an integrated part of an independently functioning organism. We would not remove a patient's biological heart, transplanted or native, simply because the patient was suffering greatly from heart failure and did not want to go on; nor should we disable his LVAD. This differs from most cases of life support, which, even if they involve devices "implanted" into the patient (like an endotracheal tube), do not support a person's independent functioning. These other life-support technologies can be used only in a professional health care setting with ongoing medical support. They are thus externally imposed treatments, not

new parts of the organism. If ventilators become backpack devices attached to a tracheostomy in otherwise independent patients, we may have to reassess our permissive attitude towards extubation.

Mr. P's essential independence leads to another objection. He needs no help to disable the LVAD. He can disconnect it from its power source himself, or fail to switch the battery when it runs out. Mr. P is presumably uncomfortable with these options because they seem to him like suicide. The fact that the patient does not want to take action on his own, however, does not authorize others to hasten his death for him. The situations in which we remove life-sustaining treatment or devices from a patient are quite limited and are generally ones in which the patient cannot act for himself and therefore requires professional medical help to carry out his autonomous wishes. Becoming involved in ending an independent patient's life—even one whose life is being prolonged by our previous actions (to which he consented)—would be impermissible. Medicine has no role in such cases.

In this case, turning off the LVAD, which supports the patient's life, seems tantamount to removing the patient's heart. I believe that, while acknowledging the burdens that Mr. P faces and the legitimacy of his desire to no longer suffer them, his physicians should respectfully decline to disable his LVAD, although they may perhaps make it clear to him that he has the means to do so himself. Furthermore, since this decision may be somewhat surprising to a patient, physicians should make their position on this matter clear during the informed consent process prior to implantation.

commentary

by Ruth L. Fischbach

Mr. P is distressed about his loss of control, his dependence on others, his loss of dignity, and being a burden to those he loves. He is in unremitting pain and profoundly fatigued. The LVAD that he was told would relieve his symptoms, improve his capacity for self-care, and enable him to lead a more active life is not effectively doing any of this. Rather, it is adding to his physical and psychological discomfort.

For any patient receiving therapy for a terminal illness, the benefits of life-sustaining measures may be outweighed by the negative consequences of treatment. Only the patient receiving the treatment can determine whether this is indeed the case. Mr. P, having weighed these benefits and burdens, now seeks to end his current medical regimen and consequent suffering.

The important question arising here, as in other end-of-life care situations, is: Once administered, can medical treatment be discontinued at the patient's request? Here, the patient wants his LVAD deactivated even though he is not facing imminent death. I believe three factors are essential to consider: the patient's self-determination, the limits of medical technology, and the physician's compassion.

After an organ is implanted, it becomes part of the patient and its functioning is relatively independent. However, an LVAD is not itself a vital organ and requires external power, anticoagulation therapy, and consistent maintenance. Discontinuing any of these will eventually lead to the patient's demise. It is important to consider that even when the LVAD is designed as destination therapy, it acts only as an adjunct to prolonging life by supporting the functioning heart. If the LVAD is disabled, death will occur due to heart failure, not medical intervention—a consolation to one who opposes suicide. In this respect, the device is similar to other forms of advanced life support, such as ventilators, which are routinely discontinued in accordance with patients' wishes in terminal extubation. To insist that Mr. P endure externally powered LVAD assistance that diminishes rather than improves his quality of life condemns him to a cruel medical fate.

Since the functioning of an LVAD depends on external power sources and pharmaceutical maintenance, removing those externalities is akin to the passive euthanasia that physicians already perform. In the end, disabling such technology will allow the patient to exchange the daily existential suffering and complications of medical intervention for a more comfortable, albeit brief, life. Mr. P is requesting that his LVAD be disabled in a medical setting where he can receive supportive care to make his final hours as comfortable as possible.

Patients increasingly make their own medical and end-of-life decisions. I believe that given the intolerable circumstances, Mr. P has the right to exercise appropriate autonomy. The LVAD is destination therapy, and the end may be when he says it should be.

LVAD technology has become an option in end-of-life care for some heart failure patients for whom transplant is not a possibility. Mr. P is a harbinger of a future where physicians grapple with requests from patients to turn off their LVADs. Thus, before implantation, physicians should employ preventive ethics by fully discussing the expected and potential outcomes, and patients should complete advance directives expressing their preferences for end-of-life care. The patient should be reassured to know that if he reaches a point where the LVAD is no longer serving his best interests and life becomes intolerable, his physician will accede to his request to disable it, ending his suffering with a peaceful death.

Physicians have an obligation to respect a competent patient's request to discontinue medical treatment. I believe it is ethically justifiable that the LVAD, in appropriate circumstances and with suitable support and comfort measures in place, be disabled by the compassionate physician. To do so is an act that will require much courage on the part of Mr. P's doctors. It is important that Mr. P, his doctors, and his family all understand how difficult this decision is, and that great compassion, beneficence, and respect for Mr. P underlie it.