Virtual Mentor
American Medical Association Journal of Ethics
June 2002, Volume 4, Number 6: 164-168.

CASE AND COMMENTARY

Right to Discontinue Treatment, Commentary 2

Commentary by Erin Egan, MD, JD and Kayhan Parsi, JD, PhD

Case

Jim, a retired attorney, is 70 and, for the last 15 years since receiving a pacemaker, has led a reasonably active life that includes some golf and occasionally throwing the football or baseball with his grandsons. He has always watched his diet and maintained a health-conscious lifestyle. He takes pride in his appearance and in looking younger than he is.

Both Jim and Dr. Austin, his internist, were shocked when an endoscopic biopsy confirmed that Jim had pancreatic cancer. Dr. Austin had been seeing Jim only every 18 or 20 months since his pacemaker surgery; he saw his cardiologist more frequently. He came to her to check out stomach pain that gradually had become constant and severe and a low-grade but persistent fever. Blood tests suggested that he had pancreatitis and a CT scan showed a mass obstructing the pancreatic duct. "Probably an impacted gall stone," Dr. Austin had said, hopefully. Then she ordered the endoscopy.

Dr. Austin was as honest as her knowledge and experience permitted in giving Jim a prognosis and explaining what he could anticipate. In her 20 years of practice, she said, she had followed about 7 patients with pancreatic cancer. The longest survival after diagnosis was over a year; the shortest was 3 weeks; the average was 3 to 6 months. But, she said, she hadn't treated such a patient in several years and didn't know how treatments and life expectancy had changed in that time. The best medical oncologist in the area, Dr. Austin said, was Dr. Maggio, and she would be happy to put a call into him right then while Jim was in her office.

Jim, appearing more calm than when the discussion began 20 minutes earlier, declined the referral, saying he didn't wish to spend his last 3 weeks to a year in doctors' offices and hospitals, undergoing and recovering from experimental treatments. "I watched my grandfather die from pancreatic cancer, and it was hell for him and everyone else. No," Jim said, "I'm going, as we say in both our professions, to put my affairs in order. Then, when things begin to go downhill, I'll come back and ask you to disconnect or turn off or however you do it, stop this ticker monitor in my chest," Jim patted his heart.

Another long discussion ensued, during which Dr. Austin cautioned that the disconnecting of Jim's pacemaker could very well not result in his immediate death.

He would go along until some arrhythmia or other event occurred. If such an event left him temporarily unconscious or disabled, she cautioned, someone would probably call 911, and Jim would end up in an ICU, connected to this and that monitor—just what he wanted to avoid.

Jim countered that he would spread the word to his wife, son, daughter, and friends that he was not to be resuscitated or sent to the hospital—"and I won't go to the mall by myself," he joked. He did not intend to tell anyone about his plan to "discontinue the pacemaker treatment" as he insisted on putting it.

Back and forth the discussion went. Dr. Austin assured Jim that she could control his pain from the cancer, even at the last. Jim said he didn't want to be in la-la-land. After the long and exhausting conversation, Jim left, asking, with the uncompromising frankness of a dying man, that she help him die in the least objectionable and "obscene" way. "We both know I'm gonna die," Jim said, "Help me not die by degrees, suffer, and drag everybody through hell. Will you, Dr. Austin?"

It occurred to Dr. Austin that she might tell Jim to ask his cardiologist for help, but she rejected that approach. If helping Jim was the right thing to do, she should have the guts to do it. If it wasn't, she shouldn't suggest that someone else do it.

Commentary 2

This is a case of a 70-year-old patient, facing a terminal illness, asking for a long-standing intervention to be discontinued. The most important fact is that Jim has the capacity to make his own health care decisions. Patients with decision-making capacity have the right to refuse any intervention or treatment, whether that treatment is believed to be life sustaining or not. Here, the fact that the patient wishes to discontinue a treatment that is unrelated to his terminal diagnosis in the hope of precipitating death is not relevant to whether this patient has the right to refuse the continued use of his pacemaker.

Autonomy is a fundamental principle of bioethics. Respect for a patient's autonomy requires that healthcare professionals honor patients' decisions and preferences, even if the professionals themselves disagree with the result. Patients with decision-making capacity are entitled to control of their bodies and deserve to make their own decisions about what care they receive. The AMA *Code of Medical Ethics* states that "[t]he principle of patient autonomy requires that physicians respect the decision to forgo life-sustaining treatment in a patient who possesses decision-making capacity."[1] The same policy statement observes that "[t]here is no ethical distinction between withdrawing and withholding life sustaining treatment.".[1]

There is no question that Jim could refuse to have the pacemaker placed now, regardless of the pancreatic cancer diagnosis. From the case description we do not know what condition led to the placement of the pacemaker. However, whether the

initial condition was life threatening or not, Jim would have the right to refuse placement of the pacemaker.

The important question to ask is, if he has the right to refuse the initiation of pacemaker treatment, then does he also have the right to have the treatment withdrawn? When medical devices are introduced into a patient's body some people believe that an ontological metamorphosis takes place. Thus, a pacemaker, like a mechanical heart valve, is part of a person in a way that a ventilator or hemodialysis is not. Turning off a pacemaker, then, is more akin to killing an individual because of this different ontological status of the technology.[2] We argue, however, that a pacemaker is a much less intrusive device than a mechanical heart valve, and is more similar to a prosthetic device that assists the patient in living their life the way they want to. Thus, the pacemaker does not become a "part" of a patient in the way that a heart valve does. So, if there is a continuum of interventions, with a heart valve on one end and a ventilator at another, the pacemaker is probably somewhere in the middle.

Therefore a patient such as Jim with a pacemaker could ethically refuse to have it maintained. Turning off the pacemaker is the only course that respects Jim's autonomy and decision-making capacity. This is a straightforward application of the principle that withdrawing and withholding treatment are ethically equivalent.

What makes this case emotionally difficult is that Jim is refusing to be evaluated for possible treatment of his cancer. Jim is suffering from abdominal pain that is reported to be constant and severe. Dr. Austin, and any responsible physician, would want to be certain that Jim's decision to withdraw treatment was not related to his pain. It would be reasonable to discuss a trial of aggressive pain management prior to discontinuing the pacemaker.

Pancreatic cancer is a diagnosis with a poor prognosis. Dr. Austin has shared her limited experience with pancreatic cancer patients with Jim. Jim also has his own experience with his grandfather's pancreatic cancer (although it is unclear when his grandfather was treated and what role, if any, an oncologist played.) Jim's refusal of a referral to an oncologist with more experience in the management, treatment, and prognosis of pancreatic cancer is therefore troubling. She has admitted that she is not up to date on the newest information on pancreatic cancer. She has properly sought to involve the appropriate expert with the knowledge needed to fully inform Jim in his decision.

The AMA *Code of Medical Ethics* Opinion 8.04 states that a physician should obtain consultation whenever the physician believes that it would be medically indicated in the care of the patient.[3] However, a patient with decision-making capacity can refuse referral as well. Dr. Austin cannot force Jim to undergo an expert evaluation of his condition any more than she could force any other treatment on him against his will. Still, she has a duty to ensure that Jim is making an informed decision. Dr. Austin can update her own knowledge on treatment and

prognosis of pancreatic cancer and she can present that information to Jim before agreeing to stop the pacemaker. While an expert may have information that is more specific to Jim's condition, she can fulfill her duty to inform by learning what she needs to know to inform Jim.

Jim also needs to be aware that stopping the pacemaker may have no effect at all on his health or his life span. Pacemakers often prevent symptoms of arrhythmias but most often do not prevent death. A defibrillator would be a device that generally treats certain fatal arrhythmias. Jim's heart may not require the help of the pacemaker all the time, but only occasionally when an arrhythmia develops. Jim may be mistaken if he believes that he will die painlessly as soon as the pacemaker is turned off. He may have new symptoms of fatigue and syncope and still be facing the progression of his pancreatic cancer. Dr. Austin must be sensitive to the principle of non-maleficence, in addition to autonomy. Non-maleficence prohibits her from harming Jim, even if he requests it. Dr. Austin needs to make sure that Jim understands that he may only worsen his situation without avoiding the unpleasant course of his disease.

If Jim is fully informed and is certain of his decision, then he has a right to discontinue treatment with the pacemaker device. Dr. Austin should honor his wishes. We can glean from the case's fact pattern that Jim has a certain trust in her, despite her lack of experience with patients suffering from pancreatic cancer. If she feels that her own ethical beliefs prevent her from assisting Jim in having the device turned off, she should refer him to someone who will help. Dr. Austin should continue to care for Jim as long as he wants to be under her care, or arrange for another physician to care for him. Ultimately, she should ensure that Jim is assisted in having the pacemaker turned off if the concerns discussed here are thoroughly addressed.

References

1. Opinion 2.20 Withholding or withdrawing life-sustaining treatment. American Medical Association *Code of Medical Ethics 1998-1999 Edition.* Chicago, IL: American Medical Association; 1998.
2. Pellegrino ED. Is it ethical to withdraw low-burden interventions in chronically ill patients? *JAMA*. 2000;284(11):1380-1382.
3. Opinion 8.04 Consultation. American Medical Association *Code of Medical Ethics 1998-1999 Edition.* Chicago, IL: American Medical Association; 1998.

Erin Egan, MD, JD is a senior associate at the Neiswanger Institute for Bioethics and Health Policy at the Stritch School of Medicine at Loyola University, Chicago and a resident in the Department of Internal Medicine, Loyola University Medical Center.

Kayhan Parsi, JD, PhD is an assistant professor at the Neiswanger Institute for Bioethics and Health Policy, Loyola University, Chicago Stritch School Of Medicine and graduate program director of an online masters program in bioethics.

The people and events in this case are fictional. Resemblance to real events or to names of people, living or dead, is entirely coincidental. The viewpoints expressed on this site are those of the authors and do not necessarily reflect the views and policies of the AMA.

Copyright 2002 American Medical Association. All rights reserved.