PERSPECTIVE

LESS IS MORE

The Elephant in the Room—Your Patient Is Dying
A Teachable Moment

Tanya H. Tajouri, MD
Division of Cardiovascular Diseases, Department of Medicine and Cardiovascular Diseases, Mayo Clinic College of Medicine, Rochester, Minnesota.

Timothy J. Moynihan, MD
Division of Medical Oncology, Mayo Clinic College of Medicine, Rochester, Minnesota.

Corresponding Author: Tanya H. Tajouri, MD, Division of Cardiovascular Diseases, Department of Medicine and Cardiovascular Diseases, Mayo Clinic, 200 First St SW, Rochester, MN 55905 (tajouri.tanya@mayo.edu).

A 55-year-old man was referred to our institution for outpatient evaluation of several long-standing symptoms, including fatigue; numbness, tingling, and weakness in his extremities; diffuse abdominal pain; watery diarrhea; unintentional weight loss; and orthostasis with recent syncopal episodes. He was extensively evaluated by colleagues in various medical specialties. On day 11 of outpatient evaluation, his first cardiac arrest occurred, requiring several minutes of resuscitation.

Testing on hospital admission included a transthoracic echocardiography, which revealed findings consistent with amyloidosis. The hematology service was consulted and recommended further invasive testing. Diagnostic studies ultimately confirmed amyloid light-chain lambda amyloidosis with nervous, cardiovascular, and gastrointestinal system involvement. On hospital day 11, the electrophysiology service was consulted for recommendations regarding possible placement of an implantable cardioverter device (ICD) given the patient's recent cardiac arrest. On hospital day 14 the ICD was implanted without complication. Thirty minutes after returning to his hospital room after implantation, the patient became unresponsive and pulseless. The ICD discharged, and his circulation spontaneously returned.

Initially, the patient continued to articulate his desire to aggressively treat the amyloidosis and its manifestations; however, on hospital day 20, he began to suffer severe panic and anxiety regarding experiencing another cardiac arrest and receiving an ICD shock. A palliative care consultation was obtained on hospital day 22. A care conference was facilitated, including the patient, his family, the primary medical team, and the hematology and palliative care teams to discuss the lethal nature of his condition and the lack of treatment options given his advanced disease. With the patient and family's permission, an open and frank discussion of his diagnosis, prognosis, and goals of care was undertaken. The goals of care were shifted from cure to palliation. The entire team worked with the patient and his family to ensure that his medical, psychosocial, and spiritual needs were met. On hospital day 25, the patient made an informed decision to change his resuscitation status to do not resuscitate and to deactivate the ICD. The following day he died peacefully in the presence of loved ones.

When caring for patients with a terminal illness, physicians are challenged with difficult discussions and decisions, and many times these ignore the "elephant in the room"[1]—the fact that the patient is dying. There are multiple drivers for this evasiveness, including lack of physician training and preparedness, the patient's and family's denial or wish to avoid difficult or painful news, and attempts to maintain hope for a different outcome.[2,3]

As exemplified in the case we describe, physicians sometimes focus solely on the disease process and how it can be treated while consciously or unconsciously avoiding the true overall prognosis and outcome, ignoring what is obvious—that the patient is dying. In fact, a recent report from the Dartmouth Atlas Project[4] noted that a large number of dying patients receive aggressive treatment until their final days, and many do not receive palliative care until within 3 days of death.

The case we describe reflects such a trend. Rather than involving palliative care services and addressing the suffering of the patient and his family shortly after his terminal diagnosis, the medical care team aggressively pursued ongoing conventional medical evaluation and therapy. An ICD was implanted without serious reflection on the entire clinical situation. The device caused harm to this patient, including diminished quality of life, significant anxiety, and possibly prolonged suffering, and it was ultimately deactivated only 10 days after the invasive implantation procedure.

Effective discussions with patients facing terminal illnesses that address the true underlying prognosis, or the so-called elephant in the room, must be initiated early and should involve members of the palliative care team. In fact, timely integration of palliative care has been shown to improve quality of life, minimize invasive interventions, diminish caregiver bereavement, and possibly even have an appreciable mortality benefit.[5,6] Earlier involvement of palliative care not only provides patients with better symptomatic relief but also allows them to make more informed decisions and gives them more time to address end-of-life issues.[7]

Published Online: December 16, 2013. doi:10.1001/jamainternmed.2013.12822.

Conflict of Interest Disclosures: None reported.

1. Quill TE. Perspectives on care at the close of life. *JAMA*. 2000;284(19):2502-2507.

2. Berry SR. Just say die. *J Clin Oncol*. 2008;26(1):157-159.

3. Larson DG, Tobin DR. End-of-life conversations. *JAMA*. 2000;284(12):1573-1578.

4. Goodman DC, Morden NE, Chang CH, et al. Trends in cancer care near the end of life. http://www.dartmouthatlas.org/downloads/reports/Cancer_brief_090413.pdf. Accessed September 5, 2013.

5. Temel JS, Greer JA, Muzikansky A, et al. Early palliative care for patients with metastatic non-small-cell lung cancer. *N Engl J Med*. 2010;363(8):733-742.

6. Wright AA, Zhang B, Ray A, et al. Associations between end-of-life discussions, patient mental health, medical care near death, and caregiver bereavement adjustment. *JAMA*. 2008;300(14):1665-1673.

7. Loprinzi CL, Johnson ME, Steer G. Doc, how much time do I have? *J Clin Oncol*. 2000;18(3):699-701.