

## **Amanda Gelman, MD**

Caring for Patients at the End of Life

### **Story From the front lines**

A woman in her 70s with a history of metastatic lung cancer presented to the emergency department with several months of increasing fatigue and poor appetite. She had initially attributed her symptoms to her experimental oral chemotherapy agent however she did not notice any improvement after self-discontinuing the medication a few weeks prior. Given her ongoing decline, living alone, and the hope that time with family would boost her energy, she decided to move to her sister's home in Colorado, where she planned to establish with a new Oncology team. However, within days of the move, her symptoms worsened and so came to the emergency department for evaluation.

In the emergency department hypotension and acute kidney injury were noted. Chest x-ray was concerning for pneumonia. The patient had reported her code status as "DNR/DNI" to the admitting team but wished to pursue additional evaluation and treatment. She was treated with antibiotics and saline though blood pressure remained low. Given concern for shock, the patient's goals of care were addressed in greater detail and the patient indicated that although she hoped she would not pass away during this admission, she did not want any aggressive measures such as any ICU-level care or hemodialysis.

Over the course of several hours her condition worsened and was transferred to the intensive care unit. An echocardiogram was ordered to assess for other causes of shock and demonstrated moderate pericardial effusion with concern for early tamponade. Her code status was reversed to full in the setting of right heart catheterization and planned pericardiocentesis; however, the latter was not pursued after her cardiac pressures on catheterization were not suggestive of tamponade. Dopamine was started through a peripheral line for blood pressure support. Despite this and other life-sustaining interventions, the patient became unresponsive. The patient's sister indicated that it was "the patient's wish not to pursue further aggressive care and that she was 'ready.'" Dopamine was discontinued and comfort care measures were initiated. The patient passed away after two hours.

### **A teachable moment**

A discussion of code status and other goals of care, is considered a standard portion of a comprehensive medical evaluation for patients being admitted to the hospital. This portion of a medical assessment presumes that individuals have differing value systems: that is, not every patient would want the same treatment in the same scenario, based on their unique priorities. The goal of this evaluation is to ensure that clinicians understand patient values and incorporate these in patient-centered treatment plans.

However assessing what a patient "really wants" is rarely straightforward and fraught with challenges. When patients are not able to make decisions for

themselves clinicians rely on advanced directives and other medico-legal documents to determine a patient's wishes. However, even patients with advanced cancers frequently do not have advanced directives.<sup>1</sup> In deceptively less complicated situations in which patients have the capacity to make their own medical decisions, as in the above case, the way that medical decisions are framed can influence patients' preferences.<sup>2</sup> Additionally, clinicians' propensity to recommend intensive treatment at the end of life differs based on clinician race, ethnicity and cultural background.<sup>3</sup> As a result, even patients who are relatively clear that they do not want invasive procedures could say otherwise depending on provider factors and, like our patient, end up spending the last days of their lives undergoing aggressive procedures. That providers are influential in patient's decision-making is evidenced by the fact that many seriously ill patients feel that they receive care that is not consistent with their preferences.<sup>4</sup>

Given that providers are in the position to influence their patients' treatment plan, which not only may lead to care that patients do not want but also increased health care spending and the risk of important physical harms, it is imperative for us to recognize our own biases and the way individual communication styles may obscure patients' true desires and lead them to potentially unwanted treatment. However, training for medical personnel surrounding end-of-life care is limited.<sup>5</sup> If we desire to provide patient-centered, and not paternalistic, care to our patients, we must start with increase training surrounding these issues, which truly are life-or-death for our patients.

1. McDonald JC, du Manoir JM, Kevork N, Le LW, Zimmermann C. Advance directives in patients with advanced cancer receiving active treatment: attitudes, prevalence, and barriers. *Supportive care in cancer : official journal of the Multinational Association of Supportive Care in Cancer*. Feb 2017;25(2):523-531.
2. Zikmund-Fisher BJ, Windschitl PD, Exe N, Ubel PA. 'I'll do what they did": social norm information and cancer treatment decisions. *Patient education and counseling*. Nov 2011;85(2):225-229.
3. Frost DW, Cook DJ, Heyland DK, Fowler RA. Patient and healthcare professional factors influencing end-of-life decision-making during critical illness: a systematic review. *Critical care medicine*. May 2011;39(5):1174-1189.
4. Covinsky KE, Fuller JD, Yaffe K, et al. Communication and decision-making in seriously ill patients: findings of the SUPPORT project. The Study to Understand Prognoses and Preferences for Outcomes and Risks of Treatments. *Journal of the American Geriatrics Society*. May 2000;48(5 Suppl):S187-193.
5. Sullivan AM, Lakoma MD, Block SD. The status of medical education in end-of-life care: a national report. *Journal of general internal medicine*. Sep 2003;18(9):685-695.

