

Last wishes and clear choices – learning how to talk about end-of-life care

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January 12, 2015

Conversations around end-of-life medical care can be challenging. Consider someone I'll call Mrs. Jones, an elderly patient with advanced heart disease. When her doctor asked her to discuss the kind of care she wanted to receive at the end of her life, Mrs. Jones said that she had devoted a lot of thought to the matter and had clear instructions she wanted her family to follow.

First Mrs. Jones wanted to be buried near her family – above ground – and she wanted her grave to be covered with yellow and white flowers. Second, she wanted to be laid out not in a dress but in her nightgown and robe. And finally, she wanted to be buried with a treasured photograph of her boyfriend, which showed a handsome young man in military uniform.

But her doctor was asking a different question. Specifically, she needed to know how Mrs. Jones wanted the medical team to care for her as she was dying. Mrs. Jones said that she hadn't thought about end-of-life care, but she would like to learn more about her options.

After discussing the choices, Mrs. Jones expressed some clear preferences. "I know for a fact that I not want to undergo chest compressions, and I don't want anyone using tubes to breathe for me or feed me." Her doctor arranged for Mrs. Jones' daughter to join the conversation. The conversation wasn't easy – Mrs. Jones and her daughter cried as they talked – but afterward they were grateful that they had shared everything so openly.

Shilpee Sinha, MD, Mrs. Jones' doctor, has these conversations every day. She is the lead physician for palliative care at Methodist Hospital in Indianapolis, where she specializes in the care of dying patients. She also teaches medical students and residents how to provide better care for patients at the end of life.

Sinha is part of a relatively small cadre of such doctors nationwide. It is estimated that only about 4,400 doctors specialize in the care of terminally ill and dying patients. The US is currently facing a shortage of as many as 18,000 of these specialists. There is only one palliative care specialist for 20,000 older adults living with severe chronic illness.

On average, 6,800 Americans die every day. The majority of deaths are anticipated. Consider that about 1.5 million people enter hospice care each year. This means there is ample opportunity for many patients to talk with their doctors and family members about end-of-life care.

Before patients can explore and express their preferences about dying they first need to have a conversation like the one between Sinha and Mrs. Jones. In too many cases, no such conversation ever takes place. Patients often don't know what to ask, or they may feel uncomfortable discussing the matter. And doctors may never broach the subject.

At one end of the spectrum, doctors can do everything possible to forestall death, including the use of chest compressions, breathing tubes, and electrical shocks to get the heart beating normally again. Of



course, such actions can be traumatic for frail and dying patients. At the opposite end, doctors can focus on keeping the patient comfortable, while allowing death to proceed naturally.

And of course, end-of-life care can involve more than just making patients comfortable. Some patients lose the ability to eat and drink, raising the question of whether to use tubes to provide artificial hydration and feedings. Another issue is how aggressively to promote the patient's comfort. For example, when patients are in pain or having trouble breathing, doctors can provide medications that ease the distress.

Another issue is ensuring that the patient's wishes are followed. This does not always happen, as orders can be lost when patients are transferred between facilities such as hospitals and nursing homes.

Fortunately, most states across the country are beginning to make available a new tool that helps doctors and patients avoid such unfortunate outcomes. It is called POLST, for Physician Orders for Limiting Scope of Treatment. First envisioned in Oregon in the early 1990s, it grew out of a recognition that patient preferences for end-of-life care were too frequently not being honored. Typically, the doctor is the one to introduce POLST into the conversation, but there is no reason patients and family members cannot do so.

The cornerstone of the program is a one-page form known in Indiana as POST. It consists of six sections, including cardiopulmonary resuscitation (CPR); a range of other medical interventions, from admission to the intensive care unit to allowing natural death; antibiotics; artificial nutrition; documentation of the person with whom the doctor discussed the options; and the doctor's signature.

The POST form helps to initiate and focus conversations between patients, families, and doctors around end-of-life care. It also fosters shared decision making, helping to ensure that all perspectives are taken into account, and ensuring that patient wishes are honored.

POST can be applied across all settings, from the hospital to the nursing home to the patient's home. It can be scanned into the patient's electronic medical record, ensuring that it is available to every health professional caring for the patient. And it does not require a notary or an attorney (or the associated fees), because it is a doctor's order.

Of course, merely filling out the form is not enough. The patient's wishes can be truly honored only if the patient and family understand the options, have the opportunity to pose questions, and trust that their wishes will be followed. In other words, POST achieves its purpose only if it is based on the kind of open and trusting relationship Dr. Sinha had developed with Mrs. Jones.

Providing such care isn't easy. "Our health care system pays handsomely for curative care," Sinha says, "but care at the end of life is probably the most poorly compensated kind that doctors provide. This can make it difficult to get hospitals and future doctors interested in it." Thanks to initiatives such as POLST and doctors such as Sinha, however, such care is finally getting more of the attention it deserves.

Disclosure Statement

Richard Gunderman does not work for, consult, own shares in or receive funding from any company or organization that would benefit from this article, and has disclosed no relevant affiliations beyond their academic appointment.

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