Refusing To Admit Defeat: Physicians’ Reluctance To Discuss End of Life Care

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Introduction

In recent years, support for patient-centered medical care has increased drastically. One aspect of patient-centered care focuses on allowing people to make educated decisions about their own end of life care. This has led to the development of the living will, the advanced directive, and most recently, the Physician Orders for Life Sustaining Treatment (POLST). Today, most states have enacted legislation creating a POLST statute or its equivalent. However, enactment of a statute is insufficient to change the culture of medicine. Physicians are trained to save people, not to let them die. During the past three months, we have conducted interviews with residents and staff at long term care facilities to learn about their experiences with end of life care. The conversations took place as part of a larger discussion of unmet need for bereavement care. In this article, we have tried to give voice to their concerns.

Background

Different states take different approaches to the provision of patient-centered end of life care. For example, California has enacted POLST legislation requiring doctors to comply with patients’ wishes, whereas in Alabama, there is no legally valid POLST form. In 2015, the Georgia legislature enacted a statute creating a document entitled Physician Orders for Life Sustaining Treatment (POLST). This form is designed to give patients an opportunity to sit down with their doctors and discuss their preferences regarding end of life care. A physician should discuss this document with a patient and offer to help fill it out “when a patient has a serious illness or condition and the attending physician’s reasoned judgment is that the patient will die within the next 365 days” or “at any time if a person has been diagnosed with dementia or another progressive, degenerative disease that attacks the brain and results in impaired memory, thinking, and behavior” (Georgia Department of Public Health: Physician Orders for Life-Sustaining Treatment, 2016) [4]. To be valid, a POLST must contain both the physician’s and the patient’s signatures. The document sets out the level of treatment that a patient would like to receive if his/her health takes a turn for the worse. Patients may designate preferences with regard to resuscitation, intravenous feeding/hydration, and ventilator use.

For this statute to achieve its goal, physicians must be willing to discuss end of life decisions with their patients. In doing so, they must admit to their patients and to themselves that they may not be able to save their patients’ lives. For physicians trained to do everything possible to save their patients, often this is very difficult (Price, 2016) [6]. In addition, physicians must choose to enforce patients’ POLSTs. The POLST is frequently described as a legally binding physician’s order (Braun, 2016) [1]. In a certain sense, this is accurate. It is a “physician’s order” and it is signed by a physician. According to the Georgia POLST statute, a “POLST form shall constitute a legally sufficient order that may be utilized by a health care provider...” (italics mine) (Physician Orders for Life-Sustaining Treatment form, 2016) [5]. Non-lawyers do not always pick up on subtleties in statutes, such as the difference between “may” and “shall.” This statute gives healthcare providers the option of enforcing this “legally sufficient order.” They may also decline to enforce it. The statute provides that physicians will not face criminal or civil liability for following or failing to follow a POLST.

Report

The POLST is a relatively new statute, but physician reluctance to discuss end of life care has been an issue for many years. In Final Independence, Erdmann talks about physician reluctance to follow patients’ wishes as enumerated in various documents including living wills and advanced directives (Erdmann, 2016) [3]. Daud et al. noted that medical schools give students minimal education with regard to end of life and palliative care, as “across the world death is still viewed as a failure” (Daud, Lee Chee, & Taib, 2016) [2]. There are various other articles that discuss physician reluctance to address end of life issues, but it is rarely discussed in the context of the POLST. Unlike advanced directives or living wills, physicians must not only enforce POLSTs, but also educate patients about them, help patients fill them out, and sign them.

In April 2016, we began a project to study bereavement
and end of life care in long term care facilities. As part of this project, we have conducted and transcribed dozens of interviews with long term residents, staff, and family members about bereavement and end of life care. In private interviews and group conversations with residents, concerns about physician reluctance to have frank end of life discussions emerged. While fear of lawsuits or religious convictions may play a role in physicians’ reluctance (especially in Catholic facilities) [Erdmann, 2016] [3], we have concluded that refusal to admit failure drives physician reluctance more than anything else. Many promoters of the POLST focus on patient education. Our interviewees suggest that success of the POLST in Georgia depends upon physicians.

In our first group interview, one long term care resident explained that she had brought a POLST form to her physician, and he had refused to fill it out with her. Our first private interview was with a woman whose husband had died less than a year before she moved to long term care. She spoke with us at length about the decline in his condition and noted that the physicians refused to give her honest answers about his husband’s impending death. She felt frustrated by this refusal, and eventually she called her daughter-in-law, who was also a physician. The daughter-in-law confirmed what she already believed: yes, her husband was dying, and he had approximately six months to live. We asked this resident why she believed that the physician was so reluctant to talk to her about her husband’s situation. She replied that she believed that the physician was “so focused on going toward the life...he didn’t even want to admit it to himself.”

The insightfulness of this resident became apparent in another interview, when we spoke with a resident who had spent his career working as a cardiothoracic surgeon. Through much of his career, he had been frustrated by physicians’ refusal to take advantage of palliative and hospice care. He explained that in his experience, physicians avoid talking to patients about death because they often see it as a personal failure. He spoke from the perspective of a cardiothoracic surgeon, stating that “congestive heart failure has a limit” but many physicians will not accept it. Physicians avoid visiting patients who are dying, which limits the care that they receive. He suggests educational seminars specifically integrating end of life care during the traditional Morbidity and Mortality conferences that take place in most hospitals across the United States. In his mind, physicians are the ones in need of education.

As part of our study, we also talked with numerous staff members, especially nurses and nursing assistants. One common reaction to grief is anger, and our interviewees noted that anger is most common among family members who do not fully understand their loved one’s situation. Therefore if physicians have had an end of life discussion with patients, and a POLST is in place, family members will be less likely to respond with surprise and anger upon the death of patients. Promoters of end of life care frequently focus on the need to educate the public about the POLST. Interviews with persons who have observed death and dying indicates that not enough is being done to engage physicians who are ambivalent about limiting care at the end of life. It is important to note that none of the older adults that we interviewed were at all squeamish about the end of life conversation. As one long term resident explained, “we all come here to die.” They do not live in denial of their own mortality. The POLST provides an excellent opportunity for physicians to act in accordance with their patients wishes. The physician community needs to acknowledge the range of views about end of life care, discuss the role of POLST as a therapeutic tool, and incorporate this perspective into training. Patients know that there are differences in the comfort-level of physicians with death and dying. Through this interview process, they make a strong case for bringing the voice of physician dissent into the larger conversation. Until this takes place, person centered care at the end of life will not take place.

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References


