ADVANCE CARE PLANNING AND POLST: PROMISE AND PITFALLS

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Much of the work of bioethics committees centers around uncertainty, or disagreements, about end-of-life care. That’s why it seems like such a no-brainer (brain death pun semi-intended) for people to want to make their wishes known ahead of time, or at least to be sure they designate someone to speak for them legally if they lose decisional capacity in the future. Yet it’s estimated that less than 30% of Californians have an advance healthcare directive (AHCD). Despite efforts like National Healthcare Decisions Day, The Conversation Project, and the Bay Area’s own Prepare for Your Care (thanks to Rebecca Sudore, MD), even in the chronically and seriously ill population there are many who never discuss their wishes with a physician or even with their family.

Since 2016, the Centers for Medicare and Medicaid Services (CMS) has allowed separate (and additional) billing for advance care planning (ACP) for Medicare beneficiaries, and we are using these codes pretty robustly based on the number of times these codes have been billed (99497 and 99498) over the past year. If you spend 16 minutes or more of a visit discussing ACP or completing forms relating to ACP, there’s no good reason not to bill these codes, which pay about $80. Medical societies including the American Academy of Hospice and Palliative Medicine, the American Geriatrics Society, and AMDA—The Society for Post-Acute and Long-Term Care Medicine, joined the AMA in advocating for adoption of payment for these codes, avoiding the “death panel” controversy this time around. Of course we should be compensated for our time helping patients navigate these complex but critically important issues!

But on the flipside, there’s been a potentially disturbing trend afoot, wherein some organizations are encouraging, or even compensating, their practitioners for completion of ACP documents, including Physician Orders for Life-Sustaining Treatment (POLST) forms, on all Medicare patients. Of course, completing an AHCD is appropriate, and recommended, for everyone 18 and up, so if that can be done in a physician’s office, that’s great. But a POLST form is a different story. According to the National POLST Paradigm, POLST is intended for patients who are seriously ill, medically frail, and for whom the answer to the “surprise question” (would the healthcare provider be surprised if the patient died in the next year?) is No. While anyone can legally complete a POLST in California (assuming they can find a physician, nurse practitioner or physician assistant to sign it), there are good reasons for the recommended limits on POLST to the seriously ill. The document is designed for people nearing the end of life and for whom the default interventions—where it is assumed that prolongation of life is the goal, within normally accepted parameters—may not be desired because of their medical condition, prognosis, and (self-)perceived quality of life.

Of course, anyone who has strong feelings about their end-of-life care, or feeding tubes, can memorialize them in a California POLST form. I know some healthy physicians who have opted to execute POLSTs for themselves specifying DNR/DNAR status, because they just don’t want to be one of those patients they’ve seen who survives CPR. But they are the exception rather than the rule. So why is there a problem with a healthy 66-year-old going to her PCP’s office and having a POLST form shoved under her nose? Well, for one thing, it’s doubtful that a rich conversation will occur in association with this exercise. We have heard of physicians basically saying to such a patient, whom we’ll call Mrs. P, “If your heart stopped, you’d want it restarted, right?” and proceeding to sign a full-code, full-care POLST form. Worse yet, they then bill a 99497 code as if this conversation took a half hour.

Beyond the obvious impropriety of this, let’s look at the other consequences. The patient may not be asked to formulate an actual AHCD, which is meant to designate her agent if she loses decisional capacity. For someone at Mrs. P’s age in good health, that is a much more important document for which to ensure completion. She may not be encouraged to discuss her more complex care wishes, such as things she would never want (for example, some people are categorically opposed to tube-feeding), with her family. And it creates a false sense of security that Mrs. P won’t have to worry because now she has filled out the appropriate legal forms. It’s true that for a patient who retains decisional capacity, she can change her POLST wishes (or any other directive to physicians) at any time.

Unfortunately, this scenario fails to consider what happens to many people on their journey between good health and death: They lose decisional capacity. Whether due to a sudden catastrophic illness or accident, or caused by the ravages of dementia, a large proportion of patients lose decisional capacity when they are close to death. If that weren’t so, there would be little work for our Bioethics Committees! And then what
happens? Let’s suppose the unfortunate Mrs. P subsequently develops Alzheimer’s disease and has become nonverbal, no longer even recognizing her own family. Worse yet, now she has been diagnosed with widely metastatic colon cancer. The only document that exists is a full-code POLST form. But a great majority of people would want a loved one to speak for them, knowing their lifelong values, goals and beliefs, if they were facing a serious or terminal illness. So this form could create a conflict for a family member like Mr. P, who knows based on many previous conversations that his wife would not have wanted her life prolonged in such a situation, yet there is a piece of paper (with a doctor’s signature on it) saying she would want it prolonged, up to and including chest compressions, shock, intubation and ventilation. Fortunately, this husband would be able to complete a new POLST on behalf of Mrs. P, assuming he was able to get past potential guilt feelings. At least under current law permitting a “legally recognized decisionmaker”—admittedly a bit of a squishy term, and one that has ethical implications—to formulate a new POLST form for a patient based on changes in medical condition, Mr. P could make his wife a DNAR, comfort-focused treatment, and enroll her in hospice as he knows she would want.

This may all change in the near future. AB 937 (Eggman) is going to be moving in the state Senate after passing the Assembly with little difficulty last year. This law would essentially “lock in” a patient like Mrs. P who completes a POLST form and subsequently loses capacity, to their last personally expressed choices. Unless this person was wise enough to also complete an advance directive naming an agent, which Mrs. P sadly did not do, even their spouse would not be able to change the requests made in that old POLST form, without obtaining a court order. This bill obviously has the potential to cause great suffering.

The stated reason for this bill? Concerns that there are cases where apparently, healthcare professionals are cherry-picking the family member who agrees with their plan, and getting them to sign a new POLST that goes against the family member’s previously expressed wishes. If that has happened, it is not legal under current law, and we really don’t need a new law to address this probably rare concern. Moreover, it invokes a sort of “death panel” conspiracy theory that has no logical basis. Why would we want a patient to get anything other than the care they would have wanted to get? To do otherwise would violate multiple ethical principles, most prominently autonomy.

The CMA has issued a letter of concern about AB 937, but as of the time of writing this article, it has not taken an oppose position. The Coalition for Compassionate Care of California and CALTCM are the only organizations that have, and there’s a good chance they will prove inadequate to defeat this well-intended but ill-advised bill. So, this may become the law of our State. It may cause much unnecessary suffering and take away the ability of loved ones to make medical decisions on behalf of our patients, using either their known expressed wishes (often expressed orally but not memorialized in a document) or substituted judgment based on their current medical status. While there is a small minority of patients who want the most aggressive medical interventions until the last possible instant of life, there are already ways for these patients to express that and avoid having a family member change it—including specifying such wishes on an AHCD or a POLST. But a majority of patients who sign Yes to CPR (full-code) on a POLST—which only applies when the person has no pulse and is not breathing—do not want that to apply ad infinitum. They mean right now if I had a cardiac arrest, I’d want you to try to revive me. Not 10 years from now when I’ve developed profound dementia and terminal, widely metastatic cancer.

Whether AB 937 passes in its current form or not, it will provide a valuable impetus to those of us who work in this arena. We need to renew our efforts to get everyone to complete an AHCD, so that they aren’t deprived of the ability to have a family member speak on their behalf when they are incapacitated. We will need to educate our colleagues to push AHCDs, which everyone should do, and save POLST forms for those who are nearing the end of life. And we need to get PCPs and nursing homes, among others, to stop pushing non-POLST-appropriate patients to complete POLSTs.

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