

FROM THE EDITOR

Death Talk

I sat with a good friend and his 85-year-old father on the first Sunday night of regular season football. In the course of conversation, his dad asked me what I was working on these days. I mentioned that I was writing a piece in response to the “death panel” rhetoric. Only partly in jest, he quipped, “You’re not in favor of them, are you?” We laughed, and I told him that neither I nor any of my colleagues in palliative and end-of-life care would ever support such a notion.

He then spoke poignantly about his wife’s death nearly two years ago. From my seat on the sofa, I faced her empty easy chair, next to his, with an afghan tossed casually over the arm as though she had just gone to the kitchen to make tea. His grief was still evident, and he spoke about the emotional turmoil that he and his adult children faced when they, at her urging, agreed to discontinue life support. His son related that although his mother had a living will, just having the document in no way prepared her – or them – for the reality of end of life in the ICU. He said, “We needed the doctors and nurses to talk to us about what was happening. And so often, the message was contradictory. We didn’t know what to do.” At this, his father looked down and said quietly, “She was ready to go. Death really isn’t the worst thing that can happen to you.”

For me, this brief conversation was emblematic of our failure to support dying patients and their families to navigate uncharted waters. *They need us to communicate* – both to listen and to offer an honest appraisal of the situation. For those who are facing end of life, death is not the worst thing that can happen to a person. For many, painful, protracted dying while tethered to technology is their greatest fear.

The political wrangling over earlier provisions in House Bill 3200 regarding advance care planning was both disturbing and encouraging. Section 1233, Advance Care Planning Consultation, would have compensated practitioners for a patient consultation to explain advance care planning, use of advance directives, roles and responsibilities of surrogates, and resources available for support. Importantly, the language describes an *optional*

consultation – not an obligation – and nothing is required of the patient. He or she is clearly free to use the information from the consultation to create an advance directive, gather more resources, ask about hospice and other options for end-of-life care – or not. Practitioners do this already; but not frequently or comprehensively, and, in some cases, without a great deal of skill or comfort.

That so much of the often rancorous debate has been at odds with the actual language in the bill is disturbing, yet the fact that we are talking about death *at all* in our preternaturally death-averse culture is, to my optimistic eye, a sign of progress. Without death talk, development of the now decades-old hospice option for those approaching end of life could not have taken place. Hospice perhaps remains the best kept secret in a fragmented and depersonalized health care system. Price of entry is a conversation about death – a conversation that many providers avoid until death is near, or never have at all. Death talk, the common pathway to improved care for the dying, remains difficult. Communication about goals of care and illness progression is the portal through which our patients and their loved ones cannot navigate without us. Despite the inroads and experience to date, there remains much work to be done to prevent and treat physical, psychosocial and spiritual suffering experienced by those at end of life and their families. Most persons die in hospitals or, increasingly, nursing homes. Pain is often poorly treated, and patient and family wishes concerning end of life care are frequently not elicited, not recorded, or not communicated among the treating professionals.

The simple truth is that we all die. Technology in the service of patient-centered goals of quality of life and longevity is moral and admirable – sometimes downright awe-inspiring. But we cannot change the fact that people die. Our patients die. Our moms and dads die. Sometimes, poignantly and painfully, our kids die. For each person, at some point, we will not be able to change the fact of death. But we have shown – again and again – that we can profoundly affect the manner in which an individual’s death is experienced and the manner in which that death

is remembered by survivors. Importantly, once the inevitability of death is acknowledged, *living* becomes the focus in end-of-life care. At that point, patient and family-centered palliative and hospice care can relieve symptoms, support patient and family wishes, listen deeply to help navigate through fears, and assure that survivors will be supported through their grief. This end of life scenario cannot be realized in the absence of communication. What is most needed to improve care of the dying is conversation. Not a single conversation, but many. Clinician discomfort discussing end of life has been well-documented,¹ and in many ways reflects our nation’s cultural discomfort with the topic of death. Studies indicate that physicians are uncomfortable making projections about the course of a disease,² particularly in non-cancer conditions where illness progression is unpredictable.³ Seriously ill patients want information about their illness trajectory,⁴ although the timing of such information is key⁵ and cultural, emotional and behavioral variations create challenges to effective communication.⁶ Clinicians struggle with honest disclosure because of overestimation of survival, concerns that patients will lose hope, and lack of personal efficacy in communicating bad news. Patients and family members have varying needs and desire for information and, even when discussion has taken place, they may not recall the interaction or the content of the conversation.

Without the benefit of honest communications, families may not recognize that death is expected, leaving them without opportunity for planning, preparation, and closure. We need capable clinicians who have been taught both the art and science of communication in the context of serious illness and value its application, even under the most difficult of circumstances. We need to see advance care planning as a process that is ongoing, changing as the patient’s circumstances of illness change – not completed in a single conversation and not sufficiently addressed in an advance directive document. We need to separate the policy discussion of advance care planning – that is, both a conversation that patients want *and* a right to participate in health care decisions that was codified by the 1991 Federal Patient Self-

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Determination Act – from the economic costs of life-prolonging intervention.

Is compensation to practitioners for advance care planning, as had been proposed in HR 3200, good policy? Perhaps. Health policy implies a consensus on issues, goals and objectives, ranking of priorities and directions for achieving those priorities. Yet policy decisions are not formulaic – they are not always made through a rational

process of discussion and evaluation, the context for the decision is often highly political, and value judgments are central to decision making.⁷ Good policy balances potential benefits and harms. If we focus on the patient at the center of the debate, it seems unequivocal that encouraging practitioners to talk to their patients about end of life in an optional, informational manner is good policy – high potential benefit with minimal, if any, harm – and that compensating them for what

can be a time-consuming endeavor, if done well, is fair policy. ■

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REFERENCES

1. Curtis JR. Communicating about end-of life care with patients and families in the intensive care unit. *Crit Care Clin.* 2004; 20(3): 363-380.
2. Christakis NA, Iwashyna TJ. Attitude and self-reported practice regarding prognostication in a national sample of interests. *Arch Int Med.* 1998; 21: 2389-95.
3. Lamont EB, Christakis NA. Complexities in prognostication in advanced cancer: "To help them live their lives they way they want to." *JAMA.* 2003; 290(1):98-104.
4. Parker SM, Clayton JM, Hancock K, Walder S, Butow PN, Carrick S, Currow D, Ghersi D, Glare P, Hagerty R, Tatterall MSN. A systematic review of prognostic/end-of-life communication with adults in the advanced stages of a life-limiting illness: patient/caregiver preferences for the content, style and timing of information. *J Pain and Symptom Manage.* 2007; 34(1):81-93.
5. Fried TR, Bradley EH, O'Leary J. Prognosis communication in serious illness: Perceptions of older patients. *J Am Geriatr Soc.* 2003; 51(10):1398-1403.
6. Lee SJ, Back AL, Block SD, Stewart SK. Enhancing physician-patient communication. *Hematology.* 2002; 1: 464-483.
7. Collins T. Health policy analysis: A simple tool for policy makers. *Public Health* 2005; 119:192-196.