THE NEW HEALTH DIALOGUE BLOG

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HEALTHCARE: Time for a Serious Discussion

by Ira Byock, MD

It's back. The provision that ignited histrionic accusations of Democratic Death Panels and a Newsweek cover about Killing Granny has been resurrected, (so to speak) tucked away on page 641 of H.R. 3962, the House's Affordable Health Care for America Act. Section 1233 would reimburse doctors for a voluntary discussion with patients about their preferences for care at the end of life. Over the summer, Chairman Max Baucus excluded such a provision from the Senate Finance Committee's health reform bill at insistence of ranking Republican, Sen. Charles Grassley. This made little sense then, and even less now that bipartisanship has collapsed.

As I scanned this 1990 page legislation, I thought of a Sarah (a pseudonym), a patient, who is a granny herself. Sarah is generally fit, the result of a healthy diet and a habit of walking five or more miles daily. So, despite her 82 years, it was a shock to her to be diagnosed with colon cancer with a metastatic tumor in her liver. When I saw her in clinic and asked if she had an advance directive, she protested, "But the oncologist said he could cure me!" True, with a combination of chemotherapy and surgery, Sarah has a chance of being cured. Still, it is fair to describe her condition as life-threatening. Yet, neither her internist, nor the oncologist, gastroenterologist, surgeon, or radiation oncologist she has seen since being diagnosed has brought the subject up.

I explained that I expected that she would do well with treatment, but that at our cancer center, we routinely ask all our patients about advance directives. We believe that discussing people's values and treatment preferences and, at a minimum, knowing who they want to speak for them if they become critically ill are components of good medical care. I hoped to reassure her by sharing that I have an advance directive. So does every adult in my family.

Recently, I introduced this topic in a medical school class on palliative care and clinical ethics. In addition to recounting my discussion with Sarah, I told the students that my two daughters, who are in their late twenties, also have advance directives. A few of the students chuckled nervously. Young adults, after all, tend to think they are invincible. Medical students are no exception.

Responding to the chuckles, I pointed out that history shows otherwise. In 2005, we all watched the Terri Schiavo case. I can't bear the thought of one of my daughters being critically ill. The only thing worse would be having a judge or elected officials meddle in our family decisions and her treatment. So when my daughters asked what I wanted for Father's Day that spring, I requested that each of them fill out an advance directive.

That got more laughs in the lecture hall. Yet this is deadly serious. The very cases that have framed American ethics and law on medical decision-making -- Karen Ann Quinlan, Nancy Cruzan, and Terri Schiavo -- were all young women in apparently good health. You don't have to be dying for these discussions to matter. You just have to be mortal.

Without an advance directive, even society's most powerful members could get dragged into a drawn out legal mess at the end of their lives. Under state law in New Hampshire, where I live and practice, if Sen. Baucus or Sen. Grassley were to suffer critical injuries in an accident, their families would not have statutory authority to speak for them -- unless an advance directive on record specifically gave them that power. Otherwise, a court, the New Hampshire legislature -- or as in the Schiavo case, the U.S. Congress -- might weigh in on whether and how long life support should be maintained.

I teach physicians-in-training that it is their responsibility to talk about advance directives with all adult patients, no matter whether these conversations are reimbursable or not. Yes, it can be uncomfortable for both doctor and patient. That's no excuse. I wonder if the senators' doctors have raised the issue with them during routine health visits. If not, why not? It is time doctors and legislators faced this issue like responsible professionals.