What’s it like to be the doctor of a patient who is going through the dying process?

Well, it’s a lot like doctoring a patient who is living. Dying is a part of living. The threshold from living to dying is a mirage. If it’s far enough in the distance you can sort of identify when dying begins to happen. But when you get close, it’s just a continuum of living.

People often have treatment goals for themselves that are, from my perspective, unrealistic or otherwise really not in their best interest. But one of the things that I live by is the notion that this is not about me. This is about them and I’m there to give them the best care I can. So I can lay things out in front of patients and families and try to help them make decisions that use the best of medical science consistent with their values, preferences, and priorities. We offer to help them through any treatment, walking each step with them. But, at the end of the day, it’s their life, not mine. I’m just here to serve. Palliative care teams are just here to serve. It’s not about us.

In your opinion, how does one know when it’s time to refuse more treatment?

Through an iterative process called shared decision-making. It’s the center of the bulls-eye of quality care for people who are seriously ill. In practice it means the physician comes to the decision-making as experts in the diagnostics and therapeutics. Patients are already experts in their...
personhood—in their values, preferences and priorities. Together, in partnership, physicians and patients determine what the best plan of care is at this point in time—and repeat the process as time passes or circumstances change.

Because life is finite, because we’re all mortal, in treating diseases like cancer or heart failure or liver failure or kidney failure or brain failure—which is what Alzheimer’s is—it is essential that we talk about what’s achievable physiologically. I love treating disease and saving people’s lives, but it’s just being honest that at some point one has to balance the potential benefits against the known burdens of a treatment and the risks of a treatment.

We talk about personalized medicine in terms of genomics but this process of applying treatments consistent with individuals’ particular values, preferences, and priorities is essential to providing the best person-centered care.

Are there any legal concerns that would discourage the doctor from saying I think it is time to let this patient die?

There are no legal concerns that keep a physician from gently being honest with a patient that this disease can no longer be held at bay, that more treatments will just bring more burdens and that, unfortunately, this is in a time of life in which you are facing the end of life. You are dying. Even using the D-word. Sometimes plain speak is just what’s needed. I don’t like doing this, but it’s part of a doctor’s job. You know, despite the miracles of modern medicine, we have yet to make a single human immortal. So I’m not apologetic for it, either. It’s just part of giving people the best care I possibly can, honestly, authentically.

Is changing how we approach death in America more of a financial-policy question or a spiritual-cultural question?

It’s a cultural question. It’s how we conceptualize health. The next big thing in American culture should be the realization that wellbeing is possible during serious illness, dying, family caregiving and even grieving. Illness, dying, caregiving and grieving certainly are stressors—and certainly carry huge burdens and risks—but it is anthropologically irrefutable that wellbeing is concomitantly possible during these times. Themes that emerge from people’s stories provide a sense of the developmental tasks of completing one’s life and architecture of personal wellbeing during these difficult times of life.

I often tell the story of Steve, a quintessential Montana cowboy, whose heavy smoking had ravaged his lungs with end-stage emphysema. Years of feeling lousy and communicating badly had ravaged his relationships with his wife and family. In exploring his anxiety, I suggested he might consider saying four things to the people he cared about: Please forgive me. I forgive you. Thank you. I love you. Steve thought it was a great idea. The next Sunday he literally read the statements before a family dinner. The result not only improved Steve’s mood, but it transformed his family. They grew closer and the history of the family shifted. A story that ends well, transforms all that has occurred.

What would you like people to say about you after you die?

I’d want my stone to read he was a good grandson and son, brother, husband and father and grandfather. And I’d like people to say, “Boy, he had a good run.”

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