

Los Angeles Times

By Brad Stulberg
December 30, 2013

Op-Ed

No one wants to talk about death, but you need to anyway

It's important to have advance directives for healthcare on file. The subject may be unpleasant, but it's better than having a loved one make a life-or-death decision in the ICU.



Hospice volunteers in Lakewood, Colo. caress the hands of terminally ill patient. While only 30% of American patients have advance directives on file, a new survey found that 79% of the patients who responded would like to talk to their doctors about end-of-life care. (John Moore / Getty Images)

By Brad Stulberg
December 30, 2013

In a culture in which speaking about death and dying has long been taboo, and with a healthcare system that does not foster such conversations, it should come as no surprise that only about 30% of Americans have advance directives for healthcare on file. Even then, an advance directive is just a paper form, and often one that is not accessible at the point of care.

More meaningful planning occurs when an individual has a healthcare agent (i.e., a person with the legal authority to make healthcare decisions on another's behalf). An effective person serving in this role must not only know and understand another's wishes for care but also be willing and able to honor them.

The consequences of forgoing this kind of planning are severe. The default in American medicine is "to do everything," which lends itself to aggressive care and intensive-care unit stays that can be painful for patients and their loved ones and harmful for the healthcare system as a whole.

YEAR IN REVIEW: Washington's 5 biggest 'fails' of 2013

In the words of a friend who is a resident, "There is nothing worse about my job than making life-or-death decisions in the ICU. It isn't the place to explore these questions for the first time, and there is never a right answer." Pull the plug (i.e., stop life-prolonging treatments) and you are giving up on Mom. Keep treating aggressively, and you are torturing her, and often to no avail.

Despite unfounded talk of so-called death panels, there's evidence that shows talking about death and dying may not be as off-limits as we think. A 2012 survey by the California Healthcare Foundation found that 79% of patients who responded want to talk about their wishes for end-of-life care with their doctors. This is especially encouraging given that structured systems to support advance-care planning conversations are growing at an increasing rate.

For instance, in La Crosse, Wis., which has been called America's best place to die because the majority of the population receives care in concordance with their values and wishes, Gundersen Health System pioneered a program called Respecting Choices. This is a systematic approach to advance-care planning built around detailed conversations led by trained facilitators that include patients and their chosen healthcare agents. These conversations result in a mutual understanding between patient and agent of the former's wishes for care, along with clear and accessible documentation of those wishes. The approach is being adopted with great success by much larger healthcare systems across the country.

YEAR IN REVIEW: Meghan Daum's overrated and underrated 2013 list

In addition to healthcare systems trying to institutionalize comprehensive advance-care planning, there has also been an increase in self-help tools that guide individuals and their families in talks about the end-of-life process. A great example is the Conversation Project (www.theconversationproject.org), which is taking part in a campaign called "Let's have dinner and talk about death." This project encourages and assists families to "transform the seemingly difficult conversation about death into an intimate shared experience."

Even outside of formal programs, everyone can talk with their families and friends (ideally including a designated healthcare agent) about their values and beliefs, and how these might translate into healthcare preferences in scenarios that we prefer not to think about. These conversations become even more important for individuals who have chronic diseases and are likely to experience a functional decline.

Having advance-care planning conversations can be hard and even scary, but what's even scarier is not having them. As we make our New Year's resolutions, make one to give yourself and your loved ones peace of mind in an area that may matter most.

Brad Stulberg is a population health consultant at a large healthcare system, where his work includes advance-care planning.

<http://www.latimes.com/opinion/commentary/la-oe-stulberg-advance-healthcare-planning-20131230,0,5263335.story#ixzz2pOyJbs2N>