Doctors Really Do Die Differently



In late 2011, I wrote an essay called "How Doctors Die." Drawing on my observations and experiences as a doctor, I reported that doctors tend to seek less end-of-life care than ordinary patients do. They know when further treatment is likely to be futile and when life would cease to be worth living. The point I wanted to make was that all of us should have the choice to die that way if we wish—at home, with family, without dramatic hospital interventions, without pain.

The response to this simple idea was overwhelming. I read thousands of comments people posted online regarding the end-of-life care of loved ones. They told of neardead relatives being assaulted with toxic drugs and painful procedures for no good reason. I am haunted by one description of a patient who could neither talk nor move, begging with her eyes for it all to stop. Thankfully, such stories are slowly becoming less common, and, with an advance directive or POLST, you have considerably better chances of having a peaceful death, if that is what you want.

While the article rarely provoked hostility, it did, among some readers, prompt skepticism. I'd written the article in a personal, anecdotal style, so I rarely made use of numbers, studies, or charts. For example, Ezra Klein, writing in *The Washington Post*, wanted to see more evidence for my assertions. "Does anyone know of data on end-oflife spending for doctors?" he asked. "Or even on the percentage of medical professionals who have signed living wills?"

This essay is an attempt to address such questions. Perhaps it should be viewed as a set of endnotes to "How Doctors Die." For every assertion of mine that was based on observation, I've looked for relevant scholarly evidence that might support or refute it. Here is what I found:

First, and most important, is the question of whether doctors, for the most part, die differently. One of the clearest indicators we have is a survey from Johns Hopkins University. It's called the Johns Hopkins Precursors Study, and it's based on the medical histories and decisions of students from the School of Medicine classes of 1948 through 1964 who volunteered to be part of the survey. According to the study, 65 percent of the doctors (or former medical students) had created an advance directive, i.e. a set of legal documents spelling out in advance what sort of end-of-life care they would like. Only about 20 percent of the public does this. When asked whether they would want cardiopulmonary resuscitation, or CPR, if they were in a chronic coma, about 90 percent of the Johns Hopkins doctors said no. Only about 25 percent of the public gives the same answer.

I also asserted in "How Doctors Die" that CPR is rarely as effective as people seem to think. What people have seen on television is at odds with happens in real life. A 1996 study published in *The New England Journal of Medicine* found that CPR as portrayed on television was successful in 75 percent of 60 cases and that 65 percent of the patients went home. In contrast, in a 2010 study of more than 95,000 cases of CPR in Japan, health professor Hideo Yasunaga and fellow researchers found that only 8 percent of patients survived for more than one month. Of these, only about 3 percent could lead a mostly normal life. A little more than 3 percent were in a vegetative state, and about 2 percent were alive but had a "poor" outcome.

My sense that there's a yearning among ordinary patients to have more peaceful deaths has been echoed in the research of University of Wisconsin-Madison nursing professor Karen Kehl. In an article called "Moving Toward Peace: An Analysis of the Concept of a Good Death," Kehl analyzed a collection of relevant articles and, based on their contents, ranked the attributes of an ideal death as follows: being in control, being comfortable, having a sense of closure, having one's values affirmed, trusting in care providers, and recognizing impending death. Hospitals cannot help with most of these things. Unfortunately, most patients do not see their wishes fulfilled. A 1998 study published in the Journal of the American Geriatrics Society looked at Medicare patients and found that, while most said they preferred to die at home, most died in hospitals. I discussed the tense, and often tragic, circumstances that surround many of the treatment decisions made in hospitals. Often, I noted, family members or medical staff effectively override the wishes of a dying patient. The studies I've found on this suggest that family plays a particularly big role in taking things in an unintended direction, especially when there's nothing in writing. A 2003 study published in the Journal of Clinical Oncology found that most patients and families agree in theory that patients should make their own end-of-life decisions, but in practice about half of families override the stated preferences of patients. They have disagreements about the use of life-sustaining measures, and they lack written documents to resolve the matter. In

contrast, a <u>2010 study</u> in *The New England Journal of Medicine* found that people with advance directives usually receive the care they've chosen.

Every doctor has heard stories about people who have had miraculous recoveries, despite a doctor's prediction. (Such stories are one reason doctors hate to make predictions.) But the sort of cases I've written about are those where all treatment has failed and the patient faces death soon. When applied to a patient in the last stages of a terminal decline, CPR is particularly ineffective. A 2010 study published in the journal Supportive Care In Cancer looked at terminal patients who wanted no CPR but got it anyway. Of the 69 patients studied, eight regained a pulse, but, 48 hours later, all were dead. Well-meaning CPR advocates talk in terms of "survival," but all the term means is that the heart again beats on its own. In the above example, survival was 11 percent, but "survival" as often understood by the public—regaining a reasonable quality of life—was zero.

We don't like to think about death. But that avoidance is one reason so many Americans fail to arrange an advance directive, even when they are severely ill. When patients of mine would come to my office accompanied by a family member, I often asked the patient how he or she wanted to die. I didn't do it because the patient was on the brink of death, or even sick. I did it because I wanted the patient to think about the question and also to make sure that a loved one got to hear the answer. Unwanted futile measures, prolonged deaths, and hospital deaths remain commonplace in America and many other places. But they don't have to be. It just requires our doctors and, no less, the rest of us to come to terms with the inevitable.

Ken Murray, MD, is Clinical Assistant Professor of Family Medicine at USC. This post was originally published at <u>Zócalo Public Square</u>, a non-profit ideas exchange that blends live events and humanities journalism.

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1 How Doctors Die

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Aug 29, 2012

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16 Responses for "Doctors Really Do Die Differently"

1. Curly Harrison, MD says:

August 30, 2012 at 9:06 am

I want to die with the EMR clicker in hand and CPOE device opened to CDS Big Data on death.

REPLY

2. RT the juicing health nut says:

August 30, 2012 at 9:11 am

Personally I think according to your article here that most doctors have the right idea. i personally do not want to be kept alive by any artificial means. i find your article very informative, in that regard, that most of us know when its time to pull the plug. In the contrast that it is presented (old age, children around the bed, life lived, die happy sort of way) it hits the nail right on the head. But i wander, are the feelings the same in cases of horrible accidents or other abrupt life endings?

REPLY

3. Barry Carol says:

August 30, 2012 at 10:43 am

I think it's interesting to note that roughly 75% of people who die in the U.S. each year are 65 or older and thus eligible for Medicare. We hear a lot of debate in this political year about how to reform Medicare so it can be sustained over the long term. One side wants to continually squeeze provider payments and have an Independent Payment Advisory Board make adjustments to covered benefits if costs rise faster than expected. The other side wants to use a premium support model for people younger than 55 and thus shift more of the financial risk onto those beneficiaries if costs grow too fast.

I wonder how much money could be saved if far more of today's elderly either executed a living will or advance directive or at least discussed with key family members what care they want and don't want in various end of life situations. It is a colossal waste to force expensive care onto a dying patient that doesn't even want it but the spouse or adjust children had no guidance about what to do because there are no appropriate documents and the subject has never been discussed.

Factor in the fact that most of the adult children haven't yet come to grips with their own mortality and the path of least resistance becomes "do everything." Living wills and discussions with family members about this subject are things today's elderly can do that will not impact their Medicare benefits one iota and will not force younger generations to take on more financial risk if medical costs rise too fast in the future. It looks like a no brainer to me that could probably be encouraged by modest financial carrots and sticks such as small discounts from or surcharges added to the current Medicare Part B premium depending on whether or not you have executed a living will and the information is stored on a registry that is readily accessible to providers and family members when needed. REPLY

4. Dr. Mike says:

August 30, 2012 at 9:03 pm

Sorry, but my desire to avoid the unpleasantness of a tort claim trumps your desire to avoid an unpleasant death.

1 Kiera says:

January 7, 2013 at 5:23 pm Ouch!

5. Barry Carol says:

August 31, 2012 at 3:59 am

Dr. Mike -

I don't understand your comment. Are you saying that avoiding a potential lawsuit requires you to ignore living wills or family requests that call for anything less than a full court press when the patient can't communicate or is no longer competent? If so, what's your recommended fix to your perceived litigation risk?

1 Dr. Mike says:

August 31, 2012 at 6:38 am

It was meant more as hyperbole to make a point – clearcut requests for limited care should always be honored – something I do all the time as a Hospice medical director. But think about why it is that "docs die differently." It is knowledge and insight that the non-medical person would not be expected to possess. But, outside of the hospice setting, my ability to present that knowledge in the form of a firm recommendation to limit care is greatly diminished by the current tort system. Tort reform has been discussed here before with a general consensus among THB readers that there is not much wrong with the way things are. Without even a desire to reform, there is not much use talking about what reform might look like. So just know that no matter how much y'all think you know about us docs, the advice we give you will always be tainted by the spectre of a tort. Too bad for you.

REPLY

6. Nora Miller says:

August 31, 2012 at 7:03 am

Experience shows that a majority of families of patients who have advanced directives feel that their family member had a more positive experience in the last months of life. This is validated by studies involving people in hospice and people who have exercised their legal right to death with dignity in those states where such laws exist. The question, it seems, is not whether ADs can be an essential part of both improving healthcare quality and managing costs, but how we do a better job of using them.

I see three criticial lessons from this discussion that both healthcare professionals and people in general can benefit from:

1. If we establish a standard of discussing an advanced directive with all people, as a part of an annual physical perhaps, then the fear factor can be minimized. If the doctor can say "we do this for everyone" then those who are healthy will not fear that the doctor is "not telling them something". I also like the idea of some kind of monetary incentive to have one in place by, say, age 55. This incentive could involve some kind of rebate or discount on services for the patient, but

definitely must provide reimbursement for doctors to take the time to do it right. 2. Note that requiring advanced directives for all people (patients and family members alike) might mean that doctors and hospitals can feel more comfortable about following them in the face of family dissent. Rather than forcing "tort reform" as a brute force method of protecting against wrongful death suits, the AD requirement might carry its own legal sanctions that addresses the ability to sue. I'm sure this is a complicated issue, but we certainly have other laws like this, so I assume the issues could be worked out in such a way as to reduce the likelihood of suits without compromising rights in cases of clear negligence. 3. I think it might help if we make a conscious effort to recognize and verbalize the difference between how and when we apply CPR and other life-saving efforts for people with otherwise healthy bodies, and how and when we do or do not use those efforts for people with terminal illnesses or unsurvivable injuries. This aligns with the important verbal distinction often made between the negative term of suicide in an otherwise physically healthy but depressed person, and positive terms like patient-controlled death, physician aid in dying, or death with dignity in an unequivocally terminal person.

Making ADs a standard, incentivized part of medical care, reducing resistance to following those ADs, and passing death with dignity laws in all states will have two critical effects: better deaths, and better outcomes for those left behind in the form of less emotional trauma, fewer needless services, and reduced costs. No one is happy when a loved one dies, but AD use clearly helps patients and families face the death more easily and with greater comfort.

1 <u>Biotunes</u> says:

January 16, 2013 at 8:29 am

And this completely rational, most would say no-brainer, outline to a more humane system for everyone, including doctors, patients, and families, is pretty much exactly what was labelled a "death panel" by the right and thus got removed from Obamacare.

7. Barry Carol says:

August 31, 2012 at 9:10 am

Nora Miller -

Thanks. Those were some of the best comments on advance directives and end of life care that I've seen in a long time.

Dr. Mike — With respect to the medical tort system, the most frustrating aspect to me is that the medical cost impact of defensive medicine and how doctors communicate with patients is impossible to quantify with any precision. While malpractice insurance premiums and court awards from malpractice suits are easy to quantify, defensive medicine just isn't. Even when it's a part of a doctor's decision in a particular instance, the decision may also be driven by patient expectations and the opportunity to generate revenue for the hospital. I strongly suggest that the cost impact is fairly significant and that the fear of litigation pervades the medical practice culture. It influences not only what services, tests, procedures and drugs doctors decide to order or recommend but

even how they communicate with patients. If we want to bend the medical cost growth curve in the future, we'll have to do a lot better in this area. That means both sensible tort reform and much more widespread use of living will and advance directives.

1 Dr. Mike says:

August 31, 2012 at 2:38 pm

Absolutely agree with you, and I would echo your compliments to Nora's comment as well.

8. Claudia says:

September 29, 2012 at 12:20 pm

As a 66 year old retired RN I have to agree with you and let you know nurses feel the same way. The public expectation and thought is when someone dies it is because the doctor or nurse did "something wrong"

They do not see death as the consequence of life. Also the most stupid comment I have heard in my career is "If there is life there's hope."

I would not want any treatment if my chances for a recovery were next to nil. You would just be wasting health care dollars that could be used on someone young who could benefit from it.

9. John Toews says:

November 28, 2012 at 1:37 am

Thank you for these excellent articles and comments. I live in Canada so some of the particulars here are different (especially financial), but the important underlying principles are the same.

My father is 91 and has become a quite frail physically and mentally (especially memory) rather suddenly. He, for some time now has been ready and preferring to die. And, as it is his wish, I concur. I see that he has virtually nothing to look forward to in life and he is the last of his cohort – wife, all siblings and siblings-inlaw' having passed on. He asked me the other day if I thought he would die abruptly or just fade away. I felt honesty was best and told him that, alas, as I understood it, the latter was the more likely. A down side to our medical prowess. Mum had the ideal death, IMO. I was with her Sunday night after a two week hospital stay that saw her rather low. That night she was her perky old self. planning on going home the next day. Well, during the night she died. In a grander sense than she had envisioned. I insisted there be no postmortem unless legally essential (having seen lots first hand). To what end? I knew what I needed to know about her death – it was due to good fortune after a lifelong battle with rheumatoid arthritis. To this day I rejoice in mom's passing – she fell asleep happy and warm. As, also that evening, my cousin had brought her a warm shawl for her perpetually cold arthritic shoulders. She was so thrilled! Though not at home, family had all visited within that last week. She was 85.

10. Shari says:

January 25, 2013 at 6:49 pm

Your article reflected exactly how I feel after working in ICUs for over 20 years as a RN and watching my grandmother die of cancer. I wish more patients and their families were informed with facts so they could make better choices for themselves.

11. <u>jacqueline friedberg</u> says:

April 12, 2013 at 12:00 am

Oh my goodness! Amazing article dude! Thank you so much, However I am having troubles with your RSS. I don't understand why I am unable to join it. Is there anyone else getting the same RSS problems? Anyone that knows the answer can you kindly respond? Thanx!!

12. ERnurse says:

July 13, 2013 at 10:39 pm

We also need to talk with families about letting go. I'll never forget doing CPR on a woman dying from cancer who was so frail that with every compression I could feel her ribs break under my hands. Meanwhile her husband of many years was standing there telling us that she could not die yet. How much kinder would it have been for the husband, and much less painful for this poor woman if someone had sat down with them before they reached this crisis point?