Knowing How Doctors Die Can Change End-Of-Life Discussions

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Heard on All Things Considered

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FROM KPCC

Nora Zamichow says if she and her husband, Mark Saylor, had known how doctors die, they might have made different treatment decisions for him toward the end of his life.
Maya Sugarman/KPCC

Dr. Kendra Fleagle Gorlitsky recalls the anguish she felt performing CPR on elderly, terminally ill patients.

It looks nothing like what we see on TV. In real life, ribs often break and few survive the ordeal.

"I felt like I was beating up people at the end of their life," she says. "I would be doing the CPR with tears coming down sometimes, and saying, 'I'm sorry, I'm sorry, goodbye.' Because I knew that it very likely not going to be successful. It just seemed a terrible way to end someone's life."

Gorlitsky now teaches medicine at the University of Southern California and says these early clinical experiences have stayed with her.

Pain And Suffering At Life's End Are Getting Worse, Not Better

Gorlitsky wants something different for herself and for her loved ones. And most other doctors do too: A Stanford University study shows almost 90 percent of doctors would forgo resuscitation and aggressive treatment if facing a terminal illness.

It was about 10 years ago, after a colleague had died swiftly and peacefully, that Dr. Ken Murray first noticed doctors die differently than the rest of us.

"He had died at home, and it occurred to me that I couldn't remember any of our colleagues who had actually died in the hospital," Murray says. "That struck me as quite odd, because I know that most people do die in hospitals."

Murray then began talking about it with other doctors.

"And I said, 'Have you noticed this phenomenon?' They thought about it, and they said, 'You know? You're right.' "

In 2011, Murray, a retired family practice physician, shared his observations in an online article that quickly went viral. The essay, "How Doctors Die," told the world that doctors are more likely to die at home with less aggressive care than most people get at the end of their lives. That's Murray's plan, too.
"I fit with the vast majority of physicians that want to have a gentle death and don't want extraordinary measures taken when they have no meaning," Murray says.

A majority of seniors report feeling the same way. Yet, they often die while hooked up to life support. And only about 1 in 10 doctors report having conversations with their patients about death.

A family portrait of Nora Zamichow, husband Mark Saylor and their daughter, Zia Saylor. *Maya Sugarman/KPCC*

One reason for the disconnect, says Dr. Babak Goldman, is that too few doctors are trained to talk about death with patients. "We're trained to prolong life," he says.

Goldman is a palliative care specialist at Providence Saint Joseph's Medical Center in Burbank, Calif., and he says that having the tough talk may feel like a doctor is letting a family down. "I think it's sometimes easier to give hope than to give reality," Goldman says.

Goldman, now 35, read Murray's essay as part of his residency. He says that he, too, would prefer to die without heroic measures, and he believes that knowing how doctors die is important information for patients.

"If they know that this is what we'd want for ourselves and for our own families, that goes a long way," he says.

In addition, Medicare does not pay doctors for end-of-life planning meetings with patients.

Hello, May I Help You Plan Your Final Months?

Nora Zamichow wishes she had read Murray's essay sooner. The Los Angeles-based freelance writer says she and her husband, Mark Saylor, likely would have made different treatment decisions about his brain tumor if they had.

Zamichow says that an arduous regimen of chemo and radiation left her 58-year-old husband unable to walk, and ultimately bedridden in his final weeks. "And at no point did any doctor say to us, 'You know, what about not treating?' "

Zamichow realized after reading Murray's essay that doing less might have offered her husband more peace in his final days.

"What Ken's article spelled out for me was, 'Wait a minute, you know, we did not get the full range of options,' she says.

But knowing how much medical intervention at the end of life is most appropriate for a particular person requires wide-ranging conversations about death. Murray says he hopes his essay will spur more physicians to initiate these difficult discussions with patients and families facing end-of-life choices.

This story is part of a reporting partnership with NPR, KPCC and Kaiser Health News.

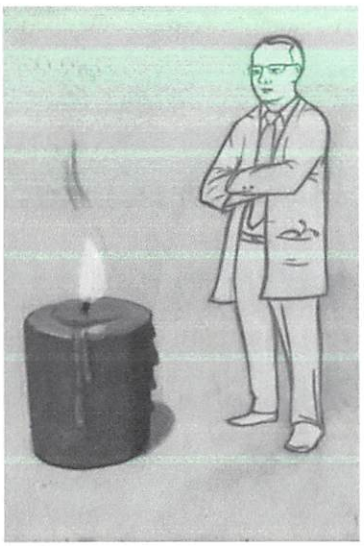
Why Doctors Die Differently

Careers in medicine have taught them the limits of treatment and the need to plan for the end

WSJ

By Ken Murray
February 25, 2012

Years ago, Charlie, a highly respected orthopedist and a mentor of mine, found a lump in his stomach. It was diagnosed as pancreatic cancer by one of the best surgeons in the country, who had developed a procedure that could triple a patient's five-year-survival odds—from 5% to 15%—albeit with a poor quality of life.



What's unusual about doctors is not how much treatment they get compared with most Americans, but how little. ARTHUR GIRON

Charlie, 68 years old, was uninterested. He went home the next day, closed his practice and never set foot in a hospital again. He focused on spending time with his family. Several months later, he died at home. He got no chemotherapy, radiation or surgical treatment. Medicare didn't spend much on him.

It's not something that we like to talk about, but doctors die, too. What's unusual about them is not how much treatment they get compared with most Americans, but how little. They know exactly what is going to happen, they know the choices, and they generally have access to any sort of medical care that they could want. But they tend to go serenely and gently.

Doctors don't want to die any more than anyone else does. But they usually have talked about the limits of modern medicine with their families. They want to make sure that, when the time comes, no heroic

measures are taken. During their last moments, they know, for instance, that they don't want someone breaking their ribs by performing cardiopulmonary resuscitation (which is what happens when CPR is done right).

In a 2003 article, Joseph J. Gallo and others looked at what physicians want when it comes to end-of-life decisions. In a survey of 765 doctors, they found that 64% had created an advanced directive—specifying what steps should and should not be taken to save their lives should they become incapacitated. That compares to only about 20% for the general public. (As one might expect, older doctors are more likely than younger doctors to have made "arrangements," as shown in a study by Paula Lester and others.)

Why such a large gap between the decisions of doctors and patients? The case of CPR is instructive. A study by Susan Diem and others of how CPR is portrayed on TV found that it was successful in 75% of the cases and that 67% of the TV patients went home. In reality, a 2010 study of more than 95,000 cases of CPR found that only 8% of patients survived for more than one month. Of these, only about 3% could lead a mostly normal life.

Unlike previous eras, when doctors simply did what they thought was best, our system is now based on what patients choose. Physicians really try to honor their patients' wishes, but when patients ask "What would you do?," we often avoid answering. We don't want to impose our views on the vulnerable.

The result is that more people receive futile "lifesaving" care, and fewer people die at home than did, say, 60 years ago. Nursing professor Karen Kehl, in an article called "Moving Toward Peace: An Analysis of the Concept of a Good Death," ranked the attributes of a graceful death, among them: being comfortable and in control, having a sense of closure, making the most of relationships and having family involved in care. Hospitals today provide few of these qualities.

Written directives can give patients far more control over how their lives end. But while most of us accept that taxes are inescapable, death is a much harder pill to swallow, which keeps the vast majority of Americans from making proper arrangements.

It doesn't have to be that way. Several years ago, at age 60, my older cousin Torch (born at home by the light of a flashlight, or torch) had a seizure. It turned out to be the result of lung cancer that had gone to his brain. We learned that with aggressive treatment, including three to five hospital visits a week for chemotherapy, he would live perhaps four months.

Torch was no doctor, but he knew that he wanted a life of quality, not just quantity. Ultimately, he decided against any treatment and simply took pills for brain swelling. He moved in with me.

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We spent the next eight months having fun together like we hadn't had in decades. We went to Disneyland, his first time, and we hung out at home. Torch was a sports nut, and he was very happy to watch sports and eat my cooking. He had no serious pain, and he remained high-spirited.

One day, he didn't wake up. He spent the next three days in a coma-like sleep and then died. The cost of his medical care for those eight months, for the one drug he was taking, was about $20.

As for me, my doctor has my choices on record. They were easy to make, as they are for most physicians. There will be no heroics, and I will go gentle into that good night. Like my mentor Charlie. Like my cousin Torch. Like so many of my fellow doctors.

—Dr. Murray is retired clinical assistant professor of family medicine at the University of Southern California. Adapted from an article originally published on Zocalo Public Square.