

## PROFESSION

### 76% of patients neglect end-of-life care planning

Despite an interest in documenting their wishes, patients are delaying these difficult talks, a new survey says.

By **KEVIN B. O'REILLY**, *amednews staff*. *Posted Feb. 27, 2012.*

More than 80% of patients believe it is important to have their end-of-life wishes in writing, yet less than a quarter of them have accomplished that planning, said a survey of nearly 1,700 California adults released in February.

"With end-of-life treatment, there is a clear gap between wishes and actions," said Mark D. Smith, MD, president and CEO of the California HealthCare Foundation, which commissioned the survey. "People consistently stress they want to die comfortably and without pain. If so, the single most important thing they can do is talk to their loved ones and physicians, and put their wishes in writing, something most Californians aren't doing."

The survey showed that 76% of respondents did not have written advance directives.

About 40% said they had talked with a loved one about what medical treatments they would want at the end of life. The top reason for avoiding the talk, respondents said, was that they had "too many other things to worry about right now."

About a quarter of respondents said they did not want to talk about death or dying. Only 3% said they had not thought about the subject.

The gap between intention and action on advance-care planning should come as no surprise, said Henry S. Perkins, MD, professor of medicine at the University of Texas Health Science Center at San Antonio.

"There's a lot of contrary human psychology to this idea," said Dr. Perkins, who teaches general internal medicine and medical ethics. "Look at how many people die without wills. Look at how many people die without making their funeral arrangements. The tendency -- and it's so human -- is to put off, put off, put off matters that aren't particularly pleasant. You can always deal with it tomorrow, and it just never gets done."

Advance directives have their limitations, because they cannot anticipate every end-of-life scenario and can precipitate as many family disputes as they resolve, Dr. Perkins said. But using the documents to prompt discussion is helpful, he added.

"They get people into the mindset that life will end," he said. "And when my life ends, it will affect the people who are closest to me. And, yes, I should take sensible steps to anticipate what that will be like."

Only 8% of the patients had ever been asked about end-of-life treatment wishes by a physician, the survey said. Broaching the topic should be part of routine care in the same way that physicians sometimes ask patients about whether they wear seatbelts while driving or helmets when bicycling, said R. Sean Morrison, MD, director of the Hertzberg Palliative Care Institute at Mount Sinai Hospital in New York.

"It's a great idea. Everyone should have [an advance directive]. But the reality is that, day to day, if I'm doing well, it's not very relevant to me," said Dr. Morrison, professor of geriatrics and medicine at Mount Sinai School of Medicine. "It's like asking an 18-year-old kid whether he's done his estate planning. For the vast majority of people, it's a complete disconnect."

Physicians should focus discussions on older patients or those with serious, life-threatening illnesses, Dr. Morrison said. He noted that Medicare does not pay for the time physicians spend on advance-care planning with patients.

Such consultations were set to be covered by Medicare under a regulation adopted by the Obama administration in November 2010, but the rule was rescinded just days after it took effect in January 2011. Conservatives had targeted a similar pay-for-counseling provision that was removed from the Patient Protection and Affordable Care Act, arguing it was an attempt to covertly ration care. The American Medical Association supported the pay-for-counseling rule.

### Measuring end-of-life care quality

Patients 65 and older were the likeliest to discuss end-of-life wishes with a loved one, with 71% having done so, the survey of California adults said. That figure is consistent with previous studies, said Dr. Morrison, who directs the National Palliative Care Research Center in New York. A study of patients with serious illnesses in Oregon found that more than 80% had completed end-of-life care planning.

While less than 40% of those surveyed in California had heard of the term "advance directive," nearly three-quarters knew of hospice care. That familiarity is a marker of the continuing growth of hospice and palliative care. Nearly 1.6 million patients received hospice care in 2010, and more than two-thirds of U.S. hospitals have palliative care programs, experts said.

The specialty's growth has come largely without external measurement of the quality of the care being provided. But the National Quality Forum in February endorsed 12 new metrics to gauge whether patients' pain and shortness of breath is being controlled adequately. The measures also touch on documentation of patients' treatment preferences, deactivation of defibrillators, comfort in dying and surveys of families' satisfaction with care.

"The field of palliative care has been lacking evidence-based quality metrics for a number of years," said Dr. Morrison, who co-chaired a steering committee that evaluated the measures. "The importance of the NQF process is that now there are measures for this rapidly growing field that are appropriate for accountability."

The data are expected to be reported publicly by the Centers for Medicare & Medicaid Services and used by payers and patients in evaluating performance.

#### ADDITIONAL INFORMATION:

### What matters most at the end of life

Patients rated these end-of-life factors as "extremely important" in a recent survey. Patients could select more than one response.

**67%:** Making sure family is not burdened financially by my care

**66%:** Being comfortable and without pain

**61%:** Being at peace spiritually

**60%:** Making sure family is not burdened by tough decisions about my care

**60%:** Having loved ones around me

**58%:** Being able to pay for the care I need

**57%:** Making sure my wishes for medical care are followed

**55%:** Not feeling alone

**44%:** Having doctors and nurses who will respect my cultural beliefs and values

**36%:** Living as long as possible

**33%:** Being at home

**32%:** Having a close relationship with my doctor

Source: "Final Chapter: Californians' Attitudes and Experiences with Death and Dying," California HealthCare Foundation,

February ([www.chcf.org/publications/2012/02/final-chapter-death-dying](http://www.chcf.org/publications/2012/02/final-chapter-death-dying))

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"Final Chapter: Californians' Attitudes and Experiences with Death and Dying," California HealthCare Foundation, February ([www.chcf.org/publications/2012/02/final-chapter-death-dying](http://www.chcf.org/publications/2012/02/final-chapter-death-dying))

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