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## Report urges end-of-life reforms

By [Carrie Seidman](#)

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Americans frequently fail to achieve the kind of death they would prefer because of a medical system that promotes aggressive intervention and doesn't pay enough attention to patient preferences, says a comprehensive report released Wednesday by the Institute of Medicine.

"Dying in America: Improving Quality and Honoring Individual Preferences Near the End of Life" says the U.S. health care system is ill-designed to meet the needs of people at the end of their lives, and that changes are necessary to provide affordable, sustainable care and better support for patients and families.

The 507-page report was issued by the IOM, the health arm of the National Academy of Sciences.

Most people do not document their end-of-life-care wishes, but even those who do often find their preferences defeated by a "fee for service" model that promotes aggressive interventions and fuels physicians' concerns about liability, the report said.

"Our current system is broken," said David Walker, a former U.S. comptroller and co-chairman of the diverse 21-member committee that produced the report. "It does not result in the honoring of individual's preferences, and it results, in many cases, in situations that cause things to become much more costly than they need be."

The report — two years in the making — advocates for a patient-centered, family-oriented approach to end of life planning that integrates traditional medical care with social services. It also calls for improved clinical training and education, greater professional collaboration, more access to and use of palliative care, and government and private incentives to encourage end-of-life planning throughout a person's lifetime.

"For most people, death does not come suddenly," said Philip Pizzo, a professor and former dean of medicine at Stanford University and committee co-chairman. "People can, and should, take control of the quality of their life through their entire life, choosing how they live and how they die, and doctors should help initiate discussions about such decisions."

Walker said all of the committee's recommendations "are intended foremost to honor an individual's values, goals and preferences."

But, he noted, even as they would help grant people the dignified death they aspire to, they would also likely result in reducing the government burden and medical costs at the end of life.

By 2030, 20 percent of the U.S. population will be older than 65. Since the IOM issued its last report on the subject in 1997, end-of-life-care costs have continued to spiral, and countermeasures — most notably the greater use of hospice and palliative care — have been inadequately available or accessed.

Meanwhile, as members of the Baby Boomer generation have begun calling for more

control over end-of-life choices, there has been political backlash against the very patient/clinician advanced planning recommended in the IOM report.

Measures proposed in 2009 for inclusion in the Affordable Care Act that would have authorized Medicare to pay for physicians counseling patients about living wills, advance directives and end-of-life options were shot down by those who raised the spectre of “death panels” that might adjudicate the timing of one’s death.

Some of the IOM recommendations could be implemented without legislation. A few private insurers have implemented reimbursement to health care providers for advanced care planning with their patients, after finding such measures to be cost-effective. Medicare, which covers 50 million Americans and whose members account for about 80 percent of deaths each year, is also considering doing so.

But other recommendations would require congressional action difficult to achieve in today’s highly partisan political climate. So while several local physicians called the IOM report comprehensive, accurate and well-intended, they were also skeptical that its recommendations could be easily achieved.

“The things that aren’t said are some of the most dramatic obstacles,” said Dr. Bruce Robinson, chief of geriatrics and head of the supportive care program at Sarasota Memorial Hospital. “For one thing, at this point in time, we work with a fee-for-service medical community that is in the business of giving people what they want. And what most people want is to hear they will live forever.”

Robinson also believes the report does not address the lack of clinicians being trained in palliative care, nor the inadequate funding covering such services.

“The report does a good job of recognizing the opportunities,” he said. “But it’s a nice job of pie in the sky of what we all want great palliative care to look like, without addressing many of the real and substantial obstacles that mean it can’t happen under the current medical system.”

Bruce Berg, dean of the Sarasota campus of Florida State University’s Medical School and co-chairman of the Bioethics Committee at Sarasota Memorial Hospital, sees a bigger hurdle in social and cultural issues that continue to “skew our view of death” in America.

“There’s a great deal in the report that is true and accurate,” Berg said. “But in our society, we also have this concept of winning, of never giving up. Physicians have been trained to save people’s lives at all costs. So not only do the physicians need to be educated, the country needs to be educated. There’s a tremendous responsibility that lies on the citizenry.”

A 2013 national survey found that 90 percent of adults in this country believe making end-of-life wishes known to family is important, but that fewer than 30 percent have done so.

And while the majority of adults say they would prefer to die at home and avoid life-sustaining efforts, one in four adults 65 or older dies in the hospital, with up to 70 percent of those incapable of making their own decisions in the last month of their lives.

The panel said that even completing advance directives does not always ensure that an individual’s preferences are carried out, unless they are detailed, specific and have been made known to a legally appointed health care surrogate.

It also advocated for a records system that could share a patient’s preferences electronically with all providers, and would be available 24 hours a day.

IOM reports generate impact in the medical world, Berg said, and he believes the recommendations will “migrate down” through health organizations, informing their planning and practices.

But that may be a long process.

“This sort of thing helps,” Berg said, “but these things are not going to happen quickly. It took us generations to get here and it’s going to take that much time again to come to something more reasonable.”

An anonymous donor, with no connection to or involvement in the committee, provided the \$1.5 million to underwrite the report and recently gave additional funding to support a yearlong public education campaign.

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