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Allan and Diane Brague of Winona, Minn., talk with Danielle Rathke about end-of-life planning at Gundersen Health System, La Crosse, Wis.

Advancing the conversation

Death panels no more: Renewed focus on end-of-life directives

Page 7

NEWS MAGAZINE

CMS to mandate bundled payments for joint replacements / Page 10

Health systems investing in technology startup firms / Page 26

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'Revolutionary' change for life's final choices would cut unwanted care

By Andis Robeznieks

When Bernard "Bud" Hammes began his career in 1984 as the clinical ethicist at Gundersen Lutheran Hospital in La Crosse, Wis., he had near-daily talks with families whose loved ones could no longer speak for themselves.

Particularly difficult cases involved elderly kidney-failure patients who had suffered debilitating strokes. Decisions needed to be made whether to continue with dialysis or whether to subject them to "heroic" measures, like rib-breaking CPR or intubations that are often more abusive than healing.

"They were paralyzed, unconscious and unresponsive," Hammes recalled. "We'd ask 'What would your mother or father want to do if they knew everything you know?' They all gave the same answer, which was: 'We don't know.' "

In 2014, CMS data found that 55% of U.S. nursing-home residents had an advance directive.

To combat what system leaders perceived as a stigma surrounding death, the Gundersen Health System's Respecting Choices advance-care planning program was born. It started with dialysis patients in 1986, and by March 1996, it was found that, of the 540 adult La Crosse residents who had died in the previous year, 96% had advance directives in their medical record.

At least partly due to Gundersen's Respecting Choices program, end-of-life medical costs in La Crosse are nearly half the national average. Now the rest of the country maybe be able to follow in La Crosse's footsteps. In its draft of the next Medicare fee schedule, the CMS has proposed paying healthcare providers for time spent with patients discussing end-of-life medical choices, starting Jan 1. The proposed rule is a remarkable comeback for a provision that was removed from healthcare reform legislation in 2009 following criticism from Sarah Palin and others who said it would ration care and create "death panels."

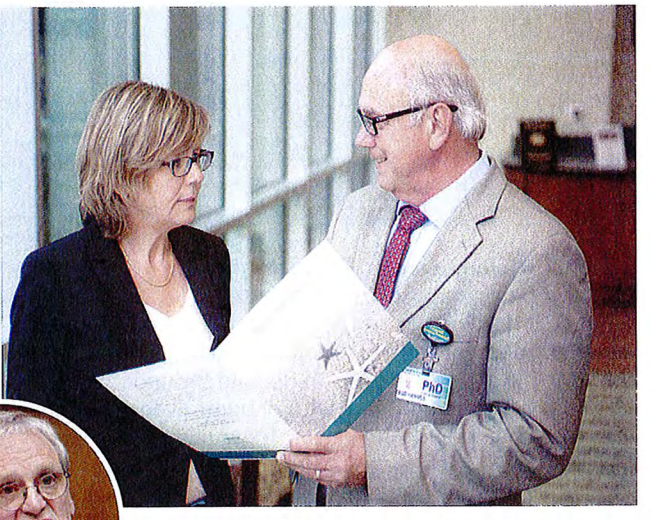
MH TAKEAWAYS

There are many challenges to expanding the growth of end-of-life directives, but experts say frank conversations would cut costs and unnecessary, sometimes harmful procedures.

But many believe the tide has turned politically. Earlier this year, Sens. Johnny Isakson (R-Ga.) and Mark Warner (D-Va.) co-sponsored a bill to pay for end-of-life talks between doctors and patients.

The proposal follows the 2014 Institute of Medicine report *"Dying in America,"* which recommended paying providers for advance-care planning that would reduce unnecessary and unwanted procedures.

Hammes called the CMS proposal an "extraordinarily important step forward," but wonders about its impact, questioning who will be reimbursed and for how much.



AP PHOTO

Rep. Earl Blumenaur, (D-Ore.) who tried to include end-of-life reimbursement in the Affordable Care Act, is mobilizing support for the Personalize Your Care Act. It would pay physicians to help patients update advance-care plans every five years.

Gundersen Health System's Bernard "Bud" Hammes talks with Ida Korfage of University Medical Center, Rotterdam, Netherlands, about the Respecting Choices program. A European Union study will use the program as a model for how to talk to patients and their families about end-of-life care.

The CMS proposes payment on two levels: one for the first 30 minutes of consultation and another for every 30-minute block after that. Hammes originally estimated this would result in payments of $54 and $50, respectively, but the CMS later announced that the figures would be approximately $86 and $75. For physicians, he said, the issue is more a matter of time than money. But healthcare administrators may say the rates are not worth an hour of a doctor's time.

Hammes hopes the CMS plan includes payment for others besides physicians. At Gundersen, a doctor starts the patient conversation and then hands it off to a nurse, social worker or chaplain with the physician available to consult.

The goal is to get patients talking about what they would want in the event of "severe and permanent" changes to their health. Patients are told that after such changes they might be uncomfortable and confused. If a medical emergency occurred, would they want treatment that kept them alive in that condition? Experts believe these conversations should happen early on.

"People can get their hands around that," Hammes said. "Asking people about specific treatments is difficult

because there's no context."

Patients' wishes are on a one-page document stored in Gundersen's electronic health-record system, and they can be shared electronically or on paper with other providers.

Physicians say that while efforts such as the online form system called eMOLST facilitate this process, it's often not easy to get area hospitals onboard.

"It's a great frustration if you take the time to talk to a patient ... (but then) no one looks at" the directive, said Dr. Nancy Girard, a solo family physician in Alexandria Bay, N.Y.

Sophia Bomba, far right, shown at her granddaughter's graduation from medical school, first began discussing healthcare proxies with her family over Thanksgiving dinner in 1992. Dr. Patricia Bomba, left, calls her mother the "patron saint of the New York MOLST program."

Rep. Earl Blumenaur (D-Ore.), who originally introduced the end-of-life reimbursement that was left out of the Affordable Care Act, is mobilizing support for the Personalize Your Care Act. His proposal would allow providers to be paid for updating voluntary advance-care planning with patients every five years. It may also include advance-planning quality measures and grant-funding opportunities.

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Illinois State Medical Society President Dr. Scott Cooper said "it will be revolutionary" to medicine if the CMS implements the payments.

Cooper, an emergency physician with the Vista Health System in Waukegan, Ill., said that without documented and accessible records declaring a patient's wishes, emergency room doctors will instinctively pull out all the stops if a patient goes into cardiac arrest.

Washington-based lawyer Charles Sabatino said advance directives can be part of an "estate-planning package" but the legal form isn't very thoughtful.

"I always tell attorneys that these standardized forms are only as good as the conversation they're based on," said Sabatino, a former president of the National Academy of Elder Law Attorneys.

Sabatino supports the Physician Orders for Life-Sustaining Treatment paradigm, or POLST (which is referred to as Medical Orders for Life-Sustaining Treatment, or MOLST, in some states), and serves as legal adviser for the National POLST Paradigm Task Force. The program is designed for people who are terminally ill. These patients have their preferences documented, and those preferences are given the authority of a medical order that must be followed.

Sabatino gave credit to organizations like Gundersen and individuals like Dr. Patricia Bomba in Rochester, N.Y., for accelerating change.

Bomba has been recognized as a leader of the movement. She worked on the committee that wrote the IOM report and serves as program director of the eMOLST electronic registry. She is also vice president and director of geriatrics for Rochester-based Excellus Blue Cross and Blue Shield.

While Sabatino called her a guru, Bomba describes her late mother, Sophia, as the "patron saint of the New York MOLST program." Bomba said her mother first brought up the subject of healthcare proxies after the family's 1992 Thanksgiving dinner, and then every year until her death in December 2007.

Bomba's daughter is a hospice and palliative-care physician, and Sophie Bomba attended her granddaughter's graduation from medical school despite having Stage 4 cancer.

Bomba has carried on her mother's message. She said a telephone survey this year found that 42% of adults in the 39-county Excellus coverage area had a proxy healthcare decisionmaker. Within the Rochester area, the average was 49% while 60% of Excellus employees had a proxy.

Excellus has been paying for advance-care planning since 2009, Bomba said. She declined to say how much the payment was, but noted that it was "time-based" rather than a flat fee.

"Advance-care planning is the process of talking to your doctor and family about what matters most, about who do you trust, and putting it in writing," she said.

Hammes agrees. But sometimes a bigger problem is the out-of-town adult child who shows up and insists "We have to do something" after the other siblings have made the agonizing decision to end their parent's treatment.

Lingering doubts over whether the right decision was made can fester for years, Hammes said. Physicians and other providers often have similar doubts.

Hammes once asked an ex-Gundersen emergency physician why he left. "He said 'That's easy, I got tired of beating up old people,' " Hammes recalled.

"What kind of life are we fighting for people to have, and does that match the kind of life they want?" asked Dr. Atul Gawande, a surgeon and author who often talks about improving the final days of life. "We need time to have these conversations. Currently, we don't reward doctors or others for taking that time."

What's New

The CMS is proposing to activate two new Current Procedural Terminology codes to be used for reimbursement for counseling patients on advance-care planning starting Jan. 1.

One covers the first 30 minutes; the other, any subsequent 30-minute blocks of time.

Using survey data from 273 physicians, the CPT codes have been valued at 1.5 and 1.4 RVUs and will pay approximately $86 and $75, respectively.

Sources: CMS, American Medical Association's Relative Value Scale Update Committee