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Medical News & Perspectives

Improving The Quality of Life at the End of Life

Rita Rubin, MA

Peggy Maguire, JD, had just started law school when her father was diagnosed with metastatic lung cancer. "We simply fought the disease tooth and nail, and my dad's quality of life suffered as a result," Maguire, chief of staff for Cambria Health Solutions in Portland, Oregon, recalled during an interview 30 years later. "We were caught completely off guard. We didn't have any conversations that might have helped us choose a different path." Despite his aggressive treatment, Maguire's father died the January after his diagnosis.

Harvard surgeon and health policy professor Atul Gawande, MD, MPH, was more fortunate when his father, also a surgeon, was diagnosed with cancer in his brain stem and spinal cord. The elder Gawande, who progressed to quadriplegia, had drawn up "the best living will ever," said Gawande, the author of *Being Mortal: Medicine and What Matters in the End* (<http://bit.ly/INSrkGG>). "We used that to guide his care every step of the way" and honor his father's wish to enjoy talking with friends over a dinner out once a week. Because his father had made it known that he preferred to avoid futile aggressive therapy, "he was a person and not a patient in the last 4 months of his life," Gawande said. "It was a fraction of the cost it would have been going down that other path."

Maguire and Gawande were among several speakers who recounted their loved ones' end-of-life stories during the recent National Action Conference (<http://bit.ly/1GJ3g8u>). The Institute of Medicine (IOM) organized the meeting as a follow-up to its consensus report "Dying in America," released last September, which found improv-

ing medical and social end-of-life services for patients and their families could enhance quality of life and result in cost savings (<http://bit.ly/1y2wuhj>).

Challenges to End-of-Life Care

At the end of their lives, **too few people have an experience like that of Gawande's father, according to the IOM report.** Among its recommendations to help fix the problem: public and private payers and care delivery organizations should cover the comprehensive care that integrates health and social services. And professional societies and others should establish standards for communication and advance care planning that payers and care delivery organizations can adopt.

But a number of barriers stand in the way of implementing the report's recommendations. Conference speakers said **obstacles include physicians' dearth of training in talking about end-of-life care, a lack of reimbursement for such discussions, and a definition of hospice care that limits its use until patients are at the brink of death.**

"These end-of-life discussions... take time, they take preparation, and we believe they need to be covered," Robert Wah, MD, president of the American Medical Association, said at the conference. "Medicare and other payers need to recognize the time that goes into this."

The Centers for Medicare & Medicaid Services (CMS) is considering introducing a code for advanced care planning, Patrick Conway, MD, CMS chief medical officer, said during the meeting. However, he offered no details about the proposal.

In 2009, Sen Mark Warner (D, Va) **introduced the Senior Navigation and Planning Act,** which would have created an advanced illness care management benefit within Medicare to promote thoughtful discussion and counseling about care options available for those with a life expectancy of 18 months or less. Warner has often said that he was motivated by his own family's experience. His mother was diagnosed with Alzheimer disease 11 years before her death and left unable to speak for the last 9 years. "We never had that conversation... what to do, how to honor her wishes" before she became ill, he recalled during the IOM meeting.

Republicans, led by former vice presidential candidate Sarah Palin, **alleged that efforts such as Warner's proposed legislation would give rise to "death panels"** that would determine who received lifesaving care and who did not, all in the name of cutting costs.

"Nothing has been more irresponsible in that whole health care debate," Warner said of what came to be called the "death panel myth" (<http://bit.ly/1Ct93cD>). He reintroduced broader end-of-life planning legislation in 2013 and plans to do it again this year, insisting, **"This is about increasing choices, not decreasing choices. It's about making sure that people can make responsible decisions and get the health care they want—no more, no less."**

The need for improved end-of-life care is a consequence of medicine's successes, which helped extend US life expectancy by about 30 years during the 20th century, Gawande said during the meet-

ing. "In 1945, most people died in their homes," he said. "Medicine didn't really have that much to offer."

However, 57% of US residents who died in 2013 were hospitalized, in a nursing home or other long-term care facility, or en route to a care facility at the time of death, according to the National Center for Health Statistics. Gawande called this trend the "medicalization of mortality."

People in the United States have come to view a good life as one of independence and health, Gawande added. "What we have lost sight of is that well-being for some people is bigger than health and survival," he said.

Hospice for Too Few, Too Late

An estimated 1.5 million to 1.6 million individuals received hospice care in the United States in 2013, according to the most recent "Facts and Figures on Hospice Care" report from the National Hospice and Palliative Care Organization (NHPCO), which represents 3300 hospice organizations (<http://bit.ly/1aDuEZ9>).

That number is increasing. In 2014, 1.6 million Medicare beneficiaries alone received hospice care, but many more likely could have benefitted, J. Donald Schumacher, PsyD, president and chief executive officer of the NHPCO, said in an interview. In most cases, patients receive hospice care in their home, according to the NHPCO

report. However, freestanding centers, hospitals, and long-term care facilities also provide hospice care, the report indicated.

Only half of beneficiaries use Medicare's hospice benefit, introduced more than 30 years ago, before they die, said David Stevenson, PhD, SM, an associate professor of health policy at Vanderbilt University, at the IOM conference. Considering that 84% of hospice patients are 65 years or older, Medicare covers the vast majority of US hospice care (<http://bit.ly/1FQbniN>).

However, stringent eligibility criteria can deter or significantly delay Medicare beneficiaries' decisions to use hospice services. Only those whose physician certifies that they have less than 6 months to live are eligible for the benefit. But predicting when a patient has only 6 months to live can be difficult.

Medicare's 6-month cutoff for hospice care was based on the estimated cost of the benefit, Richard Bernstein, MD, associate clinical professor of internal medicine, preventive medicine, and geriatrics and palliative medicine at the Icahn School of Medicine at Mount Sinai in New York, said in an interview. "It's really kind of foolhardy," he added. "People are spending so much more time in hospitals and ICUs, where there's [limited] benefit."

However, given the uncertainties in predicting the end of life, and given that intensive care unit (ICU) and hospital care may be

unavoidable under some circumstances, the American College of Critical Care Medicine issued consensus recommendations that emphasize the need for comprehensive end-of-life care in the ICU setting, especially focused on family and patient-centered decision making and care (Truog RD et al. *Crit Care Med*. 2008;36[3]:953-963).

In addition to the 6-month cutoff for hospice care, if Medicare enrollees choose hospice, they must forego therapies intended to prolong life (<http://1.usa.gov/1aiTayN>). As a result, they enter hospice "way too late," Schumacher said. In fact, he noted, a third die in their first week of receiving hospice care, two-thirds within the first 30 days.

In the United States, "some physicians are feeling as though palliative care should replace hospice care, because it does not have a time limit on it," Schumacher said at the IOM conference. Palliative care is aimed at improving quality of life by assessing physical, psychological, and spiritual aspects of patient care and can be used early in the course of illness along with therapies intended to prolong life, such as chemotherapy or radiation therapy (<http://bit.ly/1cDOTco>). The problem, Schumacher said, is that Medicare reimburses only physicians and nurses for palliative care. On the other hand, the Medicare hospice benefit covers an interdisciplinary team that typically includes social workers; home health aides; speech, physical, and occupational therapists if necessary; clergy; and bereavement counselors for the patients' family, as well as physicians and nurses. Medicare pays hospice programs a daily rate per case to cover the cost of the team.

Hospice care "needs to be viewed as less of an escape from traditional medicine and traditional care at the end of life and more as a component of high-quality care," Stevenson said.

Changing the Paradigm

The CMS has received nearly 1900 applications for health care innovation awards that will fund "care choices" models, which allow hospice and palliative care services to be delivered at the same time as curative care services, Schumacher said. "If the models are successful, we have the ability to expand or extend them," the CMS' Conway said.

Some insurance companies already have launched innovative programs to improve end-of-life care.

Care Utilization in the Last Year of Life		
	Matched Cohort of Medicare Beneficiaries With Poor-Prognosis Cancer	
	Nonhospice, % (95% CI) (n = 18 165)	Hospice, % (95% CI) (n = 18 165)
Hospital admission	65.1 (64.4-65.8)	42.3 (41.5-43.0)
Primary ICD code, discharge		
Sepsis	10.0 (9.5-10.4)	3.4 (3.1-3.7)
Pneumonia	4.4 (4.1-4.7)	2.1 (1.9-2.3)
Acute/chronic respiratory failure ^a	3.9 (3.6-4.2)	1.1 (1.0-1.3)
ICU admission	35.8 (35.1-36.5)	14.8 (14.3-15.3)
Invasive procedures	51.0 (50.3-51.7)	26.7 (26.1-27.4)
Insertion of venous catheter	21.4 (20.8-22.0)	7.0 (6.6-7.4)
Endotracheal intubation	19.3 (18.8-19.9)	2.7 (2.4-2.9)
Packed cell transfusion	15.6 (15.1-16.2)	8.7 (8.3-9.1)
Death in hospital or SNF	74.1 (73.5-74.8)	14.0 (13.5-14.5)
Acute care hospital	50.2 (49.5-51.0)	3.4 (3.2-3.7)
Long-term hospital or SNF	23.9 (23.3-24.5)	10.5 (10.1-11.0)

Abbreviations: ICD, *International Classification of Diseases*; ICU, intensive care unit; SNF, skilled nursing facility.
^a Combines ICD codes 518.81 and 518.84.
 Source: *JAMA*. 2014;312(18):1888-1896.

A recent study has shown that Medicare beneficiaries with poor-prognosis cancer receiving hospice care (Hospice) had significantly lower rates of hospitalization, ICU admission, and invasive procedures relative to those not receiving hospice care (Nonhospice) during the last year of life.

For a decade, Aetna has offered a Compassionate Care program (<http://aet.na/1aNtPOF>). "We've eliminated the requirement for commercial members to give up curative treatment in order to be eligible for hospice services," Harold L. Paz, MD, MS, executive vice president and chief medical officer at Aetna, told the audience at the IOM meeting. Plus, he said, commercially insured members are eligible for hospice care if their life expectancy is a year, not the standard 6 months.

However, Aetna must comply with CMS regulations for its Medicare members, Paz said.

Nearly 3000 Aetna Medicare members enroll in the Compassionate Care program each year, he said. In 2012, 82% of

them chose hospice care, virtually the same proportion as seen in commercially insured Aetna members, Paz said. Only a small number of commercially insured patients have opted to receive palliative care and curative care simultaneously, he said.

"Notably, we have not seen increased costs as a result of this," Paz said. In fact, **for each member who has enrolled in the Compassionate Care program, Aetna estimates it has saved about \$12 900,** Paz said. "Certainly, palliative care is less costly than curative care." Aetna has also seen "impressive results" in terms of satisfaction on the part of members and their families, he added.

As of January 1, Cambia added about 20 codes to its Medicare Advantage plan,

which pays for home health agencies, social workers, counselors, and palliative care providers that traditional fee-for-service Medicare does not, Csaba Mera, MD, deputy chief medical officer, said in an interview.

"Our view is that hospice is built into palliative care," Mera said. "But palliative care really should start much earlier. It doesn't mean that you have to stop active treatment."

"Physicians have been trained that death is the enemy," Cambia's Maguire said. "I think if we could reframe the conversation about wellness and living with quality for as long as possible, no matter your health condition, that's the cultural shift that we need to make." ■

The JAMA Forum

The Other Physician Payment Problem

Andrew B. Bindman, MD

Although the US Congress has now passed legislation to permanently repeal the controversial formula used to pay physicians for caring for patients who receive Medicare, it is ignoring an even larger payment problem in Medicaid that has implications for an even greater number of patients. The Congressional Budget Office (CBO) estimates that in 2015 there will be 66 million (<http://1.usa.gov/1HNCw7E>) individuals enrolled in Medicaid compared with 55 million (<http://1.usa.gov/1Qc7utX>) in Medicare.

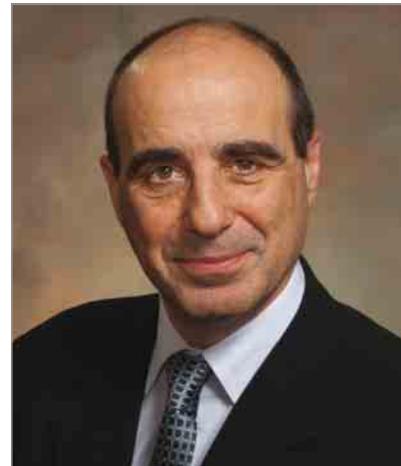
Much attention has been focused on a 21% decrease in physician payment for care provided to Medicare beneficiaries that would have occurred if Congress had not addressed the sustainable growth rate (SGR) formula used to calculate payment. Yet despite Medicaid's larger patient population, physician payments for the same services are already 34% lower in Medicaid (<http://bit.ly/1adaS00>) than they are in Medicare.

Medicaid payment rates vary widely across states, with the greatest disparity in Medicaid vs Medicare physician payments in many of the most populous states, including California, Florida, and New York. These disparities have a direct effect on physi-

cians' willingness to care for Medicaid patients. The Centers for Disease Control and Prevention found physician participation in Medicaid to be among the very lowest in these 3 states (54% in California, 56% in Florida, and 57% in New York) compared with the national average in Medicaid of 69%, (<http://1.usa.gov/11DgbrB>) even though physicians in these same states accept publicly insured patients in Medicare at rates that are not statistically different from the national average of 84%.

Why the Disparities?

Medicaid is jointly funded with resources from the federal and state governments. Although states, on average, pay only 38% of Medicaid's total costs and no state contributes more than 50% toward Medicaid physician payments for care, state Medicaid programs are allowed to determine physician payment rates. States set them low for the simple reason that this is one of the few ways that they can limit their costs for this entitlement program. States understand that low payment rates contribute to reduced physician participation and barriers to care, but they are rarely held accountable for the level of access that their programs provide.



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One way physicians and other medical professionals have attempted to combat low Medicaid payment rates has been through the federal courts, by suing state Medicaid programs to raise rates, arguing that low payment rates prevent Medicaid programs from providing adequate access to care. Federal courts have been sympathetic to the access concerns, and in several cases the courts have required states to either raise their rates or roll back proposed payment cuts.