

Financial Implications of Promoting Excellence in
End-of-Life Care
A Summary of Conference Proceedings

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A Human Face Behind a Policy Problem

After suffering for years with memory loss, Michelle Stuhl's elderly mother, Jeanne Stuhl Gider, had to move to an assisted-living facility. Jeanne had dementia, which was progressively robbing her body of function. Within a year after the move she was disoriented, barely communicating, and in diapers. Jeanne had always insisted that if the quality of her life were severely compromised by disease, she would want no life-extending medical treatment. To ensure that her mother's wishes would be honored, Michelle developed a written plan with the doctor and staff at the facility. The document stated that, in case of a medical crisis, Michelle would be called to decide whether any proposed tests or treatment were what her mother would want. But the carefully crafted plan fell through.

Michelle received a call from a staff member at the facility reporting that her mother had been sent to the hospital after repeated vomiting. There, she was put on IV fluids and subjected to a battery of tests. The doctor on call wanted to surgically remove an obstruction suspected of being cancerous. Michelle had to argue strenuously to get the surgery canceled. She called hospice, and the hospice providers found Jeanne moaning in pain. Throughout the treatment and tests in the hospital, the staff had not attended to her discomfort. Jeanne was transferred to an inpatient hospice unit where, 10 days later, her body bruised by the medical testing, she died.

A few weeks afterward, Michelle was astounded to receive a bill for more than \$22,000 for her mother's 23-hour hospitalization. She called the billing office to protest that all the procedures billed for had been administered against her mother's wishes. The official response was: "Don't worry. Medicare will pay."

Michelle Stuhl was the first speaker at a Capitol Hill meeting held in Washington, D.C., on September 9, 2002, to illustrate the mismatch between quality and amount of spending in end-of-life care, and to showcase evidence suggesting that Medicare can deliver better, more humane care for dying Americans while still not raising costs.

The conference, sponsored by The Robert Wood Johnson Foundation (RWJF), was held in part to discuss findings from the Foundation's five-year-long initiative, *Promoting Excellence in End-of-Life Care*. The initiative has funded 22 health care programs offering palliative care—care to relieve the physical, emotional and spiritual suffering related to dying and to improve quality of life—earlier on in a patient's illness than is currently allowed under Medicare regulations. By introducing palliative care early, and concurrently with life-extending care, the programs were able to maintain or lower costs through reduced hospital stays and less use of high-tech care.

After presenting promising findings from some small-scale, institution-based studies, speakers at the meeting called for the federal government to undertake large-scale demonstration programs within Medicare to see if the findings hold up when care models are applied to the general population.

The Mismatch Between Quality and Cost

John Wennberg, M.D., director of the Center for the Evaluative Clinical Sciences at Dartmouth Medical School and a nationally recognized expert in health care usage and spending patterns, presented evidence to illustrate that when it comes to Medicare spending for end-of-life care, more is not necessarily better. The data he used, based on nationwide Medicare data from the early to mid-1990s, revealed great variations in and systematic overuse of hospitalization, stays in intensive care units (ICUs) and physician visits—particularly at the end of life—and with no measurable evidence on patient outcomes. Instead, he said, it appears the more that services are available, the more they are used.

For example, between 1995 and 1996 in Miami, Florida, and in the borough of Manhattan in New York City, more than 30 percent of patients saw 10 or more physicians in their last six months of life. For equivalent groups of Medicare patients in their last six months of life in Missoula, Montana, Iowa City, Iowa, and Portland, Oregon, the rate was barely 7 percent. In the same period, the average number of visits to medical specialists for Medicare enrollees during their last six months also varied tremendously—from 25 visits per patient in Miami to fewer than four in Portland. Furthermore, the percentage of Medicare enrollees who were admitted to an ICU during their last six months of life ranged from nearly 50 percent in Miami, to less than 23 percent in Minneapolis, Missoula and Portland. Yet, according to Wennberg, the number of ICU visits had no impact on life expectancy.

In terms of Medicare costs in 1996, spending per enrollee ranged from \$8,414 in Miami to \$3,431 in Minneapolis. “On an age/sex/race and illness-adjusted basis,” Wennberg said, “total Medicare-program spending would be reduced by 33 percent if the benchmarks for the efficient areas [such as Missoula and Minneapolis] were the national norm.”

Policy Reform Goal: Remove Medicare’s “Terrible Choice”

Why the mismatch between quality and spending? Ira Byock, M.D., director of *Promoting Excellence in End-of-Life Care*, pointed to Medicare’s reimbursement rules, which drive doctors to choose futile and expensive end-of-life procedures over palliative care, which is applied early on in a patient’s illness and focuses on quality of life.

Byock offered the definition of palliative care that has been developed by the Public Policy Committee of the National Hospice and Palliative Care Organization, which represents the hospice industry: “Palliative care is interdisciplinary care for persons with life-threatening illness or injury which addresses physical, emotional, social and spiritual needs and seeks to improve quality of life for the ill person and his or her family.” Palliative care is a discipline, he said, and hospice care is the best-developed system of delivering it.

“The general public expects that comfort and quality of life are simply part of good medical care,” Byock said. People expect “that when you go to a reputable medical center or respected doctor’s office and practice, things like clear communication, ethical decision-making, care planning that respects a person’s values and preferences, coordination of care between visits and

among providers, crisis prevention and early crisis management are all routine. Delivering on those reasonable expectations is the challenge that really brings us here today.”

Byock said that there are two reasons why the health care system often promotes life-prolonging care without attention to patients’ comfort and quality of life. First, he noted, physicians have been trained to save lives, and their practice patterns and the systems in which they work support this exclusive focus. Few physicians, he said, have been taught how to have an emotionally difficult and time-consuming discussion with patients about the alternatives for care. Because of the pressures of a busy practice, it is often easier for a doctor to admit a patient to the ICU than to have such a discussion.

Second, the payment incentives within Medicare and most private health plans support a focus on acute, life-saving care, while reimbursements for discussions with patients are set so low as to be actual financial disincentives. (Doctors must constantly meet productivity goals to support employee costs and office overhead.)

An even greater payment problem is that Medicare and most private health plans require a patient to give up life-saving care before they will make a hospice plan available. This policy has come to be known in clinical circles as *the terrible choice*.

Byock said that the terrible choice creates a Catch-22 situation in which the emotional and spiritual support intended to help a person let go of death-prolonging care is available only once the patient has decided to forgo life. It has also created a model of care that focuses on comfort and quality of life only *after* aggressive life-saving treatments have been discontinued, rather than during that period.

The requirement to choose was built into Medicare by Congress in the early 1980s, because legislators demanded cost-neutrality and assumed that if both types of care were available simultaneously, costs would rise. Current research suggests otherwise, Byock said. Several directors of *Promoting Excellence in End-of-Life Care* demonstrations tracked costs as they conducted their programs, and two of the five demonstration programs featured at the conference are illustrative.

Promising Strategies: Preliminary Findings

Project #1: Dorothy Deremo, president and CEO of the Hospice of Michigan, described a collaboration between the hospice and the University of Michigan Comprehensive Cancer Center that was supported by a grant from *Promoting Excellence*. This project tested both the quality and cost-effectiveness of providing hospice care simultaneously with cancer treatments.

Project #1 Description: Hospice of Michigan teamed up with the University of Michigan, two other tertiary care centers, and a number of private physicians across the state to conduct a randomized clinical trial. An experimental group received aggressive anti-cancer treatment along with palliative care, while a control group received cancer treatment only. The program has served more than 160 patients with breast, prostate, lung, colon, pancreas, bladder and skin cancers. A full-time nurse acting as palliative care coordinator ensures that patients in the

experimental group are offered a coordinated range of emotional, spiritual, social and other support services.

Project #1 Findings (based on 55 subjects who have died at this point in the study):

The experimental group reported a higher quality of life and their caregivers reported a lower caregiver burden than was the case with the control group. Emergency-room visits averaged .8 per patient in the experimental group; compared with 1.07 visits per patient in the control group.

Hospital admissions were 1.65 per patient on average for the experimental group, and 1.83 per patient for the control group.

Average length of stay per hospital visit was 7.7 days for the experimental group and 9.9 days for the control group.

Unexpectedly, the experimental group also tended to report higher levels of pain. Deremo believes this may be due to the close relationship patients developed with the palliative care coordinator, which may have made them more likely to report actual pain levels, but further study will be necessary.

Another unexpected finding is that preliminary results suggest that patients in the experimental group lived longer than did those in the control group.

Average hospitalization costs for the experimental group were \$8,974 per patient; compared with \$13,126 for the control group. Average total costs per patient were \$12,682 for the experimental group, compared with \$19,790 for the control group.

The cost findings did not include the cost of prescription drugs for either group, nor the service costs for palliative care. Deremo believes that if these two factors were added to the equation, cost savings for the experimental group would be lower; or, at worst, total care costs for both groups might be the same, despite the fact that the experimental group received more extensive services and achieved generally superior outcomes.

Project #2: Ashley Micklethwaite, grant program officer with St. John's Regional Medical Center in Joplin, Missouri, described her hospital's *End-of-Life* program, which is part of a comprehensive set of palliative care programs offered by the hospital. They provide case management coupled with attention to comfort and quality of life for patients with life-threatening illnesses, introducing this care far sooner than is commonplace—often up to two years before death.

Project #2 Description: St. John's Regional Medical Center is a 367-bed hospital serving 19 mostly rural counties in Missouri, Arkansas and Kansas. The *End-of-Life* program, begun in 2000, has a full-time palliative care coordinator who works with the hospital's nurses, social workers, therapists, pastors and administrators. The coordinator identifies dying patients and connects them with a range of palliative-care services, as needed. Care is initiated in the hospital, and patients are usually referred from the ICU and the emergency room. Patients spend an

average of three days in the program; those who stabilize are often discharged to home hospice care.

Project #2 Findings (based on a sample of 197 program patients who died):

Family members of decedents were interviewed; 97 percent reported a high level of satisfaction with pain control. Overall, family members rated the program at a satisfaction level of 4.8 on a 5-point scale.

This project has also yielded a net annual savings to the hospital of \$108,467, after accounting for program costs. For the first 197 patients served by the program, average savings per patient were \$1,604.

Project #3: Richard Brumley, M.D., is physician-in-chief with Kaiser Hospice and Home Health in Downey, California. His program offers home hospice care concurrently with curative and restorative care to patients suffering with congestive heart failure, chronic obstructive pulmonary disease and cancer who are likely to have up to a year to live.

Project #3 Description: The program features a team of physicians, social workers, nurses and aides all of whom make home visits to the patient to develop treatment goals and provide care (including help with daily living activities, such as bathing). Providers also offer emotional and social support to the family, as well as respite care. The program's goals are to prevent any unnecessary hospitalizations and ultimately to allow the patient to die at home, if possible. A comparison study of the program involving 500 patients was conducted between 1999 and 2001. The study compared patients in Brumley's program who received palliative care concurrently with curative and restorative care with a control group that did not receive palliative care.

Project #3 Findings (based on 300 participating patients who died):

For the first two months after entering the study, patients who received palliative care showed a significant increase in satisfaction with care, while patients in the control group showed no increase. Data collected on patients after one to 12 months in the program showed that palliative care patients, compared with patients in the control group, had fewer physician visits (5.3 vs. 11.1); fewer ER visits (0.9 vs. 2.3); and fewer days in a skilled nursing facility (0.9 vs. 4.6).

More than 87 percent of the patients in the palliative care group died at home, compared with less than 57 percent of patients in the control group. The average daily cost per patient in the palliative care group was \$62 compared with \$133 per patient in the control group. Total per-patient costs for those in palliative care group were 45 percent lower than for those in the control group (\$7,990 vs. \$14,570).

Projects #4 & #5: Diane Meier, M.D., is director of the Lillian and Benjamin Hertzberg Palliative Care Institute at the Mt. Sinai Medical Center, an acute-care tertiary hospital in New York City. She discussed the institute's program, as well as another program—a *Promoting Excellence* partnership linking Mt. Sinai with Franklin Health Inc. (a private, complex-care

management firm) and Blue Cross Blue Shield of South Carolina—designed to provide community-based, palliative care to patients with advanced and complex illnesses.

Project #4 Description: Operating in one of the busiest hospitals in the nation, the Palliative Care Institute at Mt. Sinai provides a team of nurses and physicians who consult with hospital providers on how to manage pain and other symptoms, and how to talk with patients and family members about making sound decisions regarding life-sustaining care. Patients can receive palliative services along with curative, or life-extending, care. The program includes a four-bed inpatient unit for patients with severe symptoms, as well as for those patients and families who need help coping with life-closure issues. About half of the patients in the project go home or to a nursing home or hospice.

Project #4 Findings: This project proved able to improve symptoms for all patients experiencing severe, moderate or mild levels of pain, nausea and breathing problems. Of family members interviewed after a patient's death, 95 percent said they were satisfied with the overall care provided. In particular, more than 90 percent said they were satisfied with pain and other symptom control; 84 percent said they were satisfied with the support provided for families in distress and anxiety; and 89 percent said they were satisfied with the support of the patient's quality of life.

Cost impact was based on the 519 Medicare patients who died at Mt. Sinai in 2001—with and without the help of the palliative care program. The palliative care program resulted in substantial savings for Mt. Sinai through reduced length of stay for seriously ill patients. Palliative care patients spent 360 fewer days in Mt. Sinai than did Medicare patients who died without the program. Cost savings from palliative care were \$757,555 for patients who stayed longer than 14 days in the hospital and \$455,936 for those who stayed more than 28 days.

Project #5 Description: In this partnership between the Hertzberg Palliative Care Institute (the Institute provides expertise and training in palliative care and symptom management), Blue Cross Blue Shield of South Carolina and Franklin Health Inc., a private, complex-care management firm, Blue Cross enrollees with complex and advanced illnesses are identified and referred to Franklin Health. A Franklin Health nurse case manager makes a two-hour visit to the patient's home, and helps the patient and family develop treatment goals. Subsequently, the case manager coordinates care via telephone contacts. Case managers are allowed to be flexible with health plan benefits. For example, to avoid hospitalization they can pay for transportation to and from radiation therapy, or purchase an air conditioner for a patient with breathing problems. Program goals are to increase patient satisfaction with care and to reduce health care costs through lower utilization.

Project #5 Findings: Based on a three-year study, Franklin Health patients had fewer hospital days (2.3 days less, on average), and fewer hospital admissions than other health-plan enrollees with complex and advanced illnesses. Chemotherapy and radiation use, however, were at similar levels. During the third year of the study, 83 percent of 184 patients in the project reported that they were extremely satisfied with the care they received, compared with 80 percent of patients receiving usual care.

The program yielded substantial savings. By the third year of the study, per-patient savings for those under case management were \$33,179; or about 17 percent lower than costs for those who did not receive Franklin Health services.

Experts Respond: The Consumer's Perspective

Ellen Stovall, founder and president of the National Coalition of Cancer Survivorship, commented that the reason cancer treatment is so focused on technology is that “we’re dealing with a very perverse reimbursement system. When you’ve got a reimbursement system where physicians are almost totally dependent on the provision of chemotherapy as the economic basis on which they finance the practice of their patients, their incentive is to give more chemotherapy.”

Stovall said that many oncologists have agreed that the solution to this problem is to create specific reimbursement for palliative care and symptom management, and the provider behavior will change. Training physicians to practice a different way is also crucial.

Adding another consumer perspective, John Rother, director of policy and strategy for AARP, noted that AARP will be placing “renewed emphasis” on end-of-life education and policy change. He said his number-one take-home message from the data presented at the conference was the importance of flexibility in reimbursement, and made a plea for removing the terrible choice in Medicare and for Medicare prescription-drug coverage in general.

Rother suggested that physicians should be educated in end-of-life care and offered incentive payments to provide palliative care because the physician is “the key mediator” in decisions about life-extending care. He also endorsed pursuing demonstration programs at the federal level. “It’s time now,” he said, “for the federal government to get involved in a much bigger way to fund larger-scale demonstrations, to see if the very promising results presented here will hold up.”

Experts Respond: The Provider Perspective

Brad Stuart, M.D., medical director of Sutter Visiting Nurse Association and Hospice in Emeryville, California, offered a provider perspective on changes needed to allow palliative care to be provided earlier in a patient’s illness.

First, he said, patients must be able to make choices about the direction of their treatment, but they “need to be educated to know what those choices mean.” Advance care planning that involves this education—which he terms “transition management”—is critical. Transition management is for people who are seriously ill but not yet terminal. The challenge, he said, is to tweak current Medicare regulations in a way that allows for such management, so that ultimately patients can avoid unnecessary hospitalizations and get help to die at home.

According to Stuart, home health care could be a key factor in transition management. It is already a Medicare benefit, but is geared to promote recovery and patient safety, with little emphasis on discussion with patients about their future options for care. The home care benefit often ends when patients’ acute-care needs are met.

While cautioning about the risk of fraud and abuse, Stuart said that a demonstration program could test a new definition of the skilled-need requirement in Medicare. “Advanced care planning and contingency planning to keep people out of the hospital is just as much of a skilled need as changing catheters,” he said.

Experts Respond: A Medicare Perspective

Tom Hoyer, director of the Chronic Care Policy Group in the Center for Medicare Management at the Centers for Medicare and Medicaid Services (CMS) in Baltimore, Maryland, made a number of comments that he said were personal and did not reflect the views at CMS. He mentioned a number of policy-reform options that he regards as worth considering: hospice-rate reform; making hospice a mandatory benefit under Medicare+Choice; Medicare coverage for prescription drugs; separate payment for case management; and hospice consultations with hospitals and nursing homes.

Hoyer also said that the model closest to meeting advocates’ desires for better end-of-life care already exists and has been put into limited use: The Program of All Inclusive Care for the Elderly (PACE), he noted, has been a permanent part of Medicare, and a Medicaid funding option, since 1997. A capitated form of managed care, it provides a seemingly endless range of services for the entire array of patient needs. “It fumigates houses and de-fleas dogs,” Hoyer said. “It’s Meals on Wheels. It does what it takes to keep the individual in the home and community for as long as possible.”

But the public and providers are not ready to use this model, he said, because they are not yet comfortable with accepting death and the “holistic approach that characterizes hospice care.” He said that for the model to work, staff and patients must share a common vision of end-of-life care, and choices.

He said he would be interested in considering demonstration projects and Medicare refinements to improve end-of-life care, but that the public has to demand fresh approaches. “Medicare responds to demands,” he said. “It doesn’t respond as well to the notion that if you build it, they will come.”

Next Steps: Moving from Research to Policy

In summing up, Ira Byock observed that, with the graying of the American population and the rise in health costs, it is understandable that any Medicare reform “to encourage concurrent, life-prolonging and palliative care for patients with serious, life-limiting illnesses” would run headlong into questions. If one were to project costs for such a benefit simply by adding the cost of palliative care to the cost of life-prolonging care, he said, government officials would conclude that such a benefit package is unaffordable.

But he pointed out that the results of the *Promoting Excellence* projects and other models presented at the conference suggest that improved quality and controlled costs are consistently the result when palliative care is introduced early, concurrently with life-prolonging care. The challenge, he said, is to align access to services with quality care and controlled costs.

In agreement with earlier speakers at the conference, Byock said that Medicare's end-of-life care payment structure needs to be overhauled. He joined them in calling for a wide-scale government test of the palliative-care models that have been shown on a small scale to improve care quality and save money. Such demonstration programs would provide the data needed to redesign the way in which Medicare pays for end-of-life care.

Byock suggested that CMS could develop demonstrations in five to eight regions of the country, each encompassing perhaps a half million Medicare recipients. In each region Medicare rules would be temporarily altered so that specific models of palliative care could be tested. One region might test the feasibility of a tiered Medicare hospice benefit that could be adjusted according to the severity of a patient's illness. Other regions might test a Medicare+Choice model including palliative care that could be evaluated by the same predetermined measures of access, quality and costs. Another region might test the feasibility of introducing palliative care at the point of diagnosis of a chronic illness, as described in the *Medicaring* model developed by Joanne Lynn, M.D.

"The time to act is now," Byock said. "We have the potential for providing not only ethically sound and medically competent care, but also care that offers so much more in terms of comfort and quality of life."