

# ALIGNING VALUES WITH PRACTICE

**M**r. Jessop, a 70-year-old veteran, spent his last 13 days of life in the ICU. Throughout his life he was fiercely independent. Although he had neither a living will nor power of attorney for health care, he had often told his wife and family that he wasn't afraid of dying. Years earlier, his brother had suffered a stroke during heart surgery. After visiting him, Mr. Jessop had remarked to his family that he would rather die than end up strapped to a bed in an ICU. Now that was exactly what was happening.

His wife of 38 years and his adult children felt bewildered; it had all happened so fast. But in the last days of his life they became angry—at themselves, because they felt they had betrayed Mr. Jessop's trust, and at his doctors for never really giving their family a say in critical treatment decisions.

But how could this have occurred? Ironically, it was nobody's fault—or at least no one person's fault. The causes of this situation are rooted in our systems, assumptions, and routine ways of acting.

Mr. Jessop had been a vigorous man all his life, but chronic bronchitis and advanced congestive heart failure conspired to erode his health when he was in his 60s. He received good medical care from his cardiologist and pulmonologist; the correct treatments and medications, in correct doses,



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*The  
“Promoting  
Excellence”  
Program  
Demonstrates  
the  
Practicality  
of Palliative  
Care for  
Patients,  
Families,  
and  
Caregivers*

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were given for his condition at each point in time. One winter he was hospitalized three times in as many months for episodes of bronchitis and pulmonary edema. He was intent on getting better. Helped by around-the-clock, low-flow oxygen via a nasal cannula, and inhalers, diuretics, and occasional antibiotics, Mr. Jessop was able to care for himself and enjoy most days.

Two weeks before his death, his breathing gradually worsened. While moving his bowels one morning, he suddenly became severely short of breath. His wife, not knowing what else to do, called an ambulance. Paramedics, having found Mr. Jessop cyanotic and struggling for breath, intubated him en route to the hospital. He was placed on a ventilator and admitted to the ICU. He initially improved and regained consciousness, but within a few hours his blood pressure dropped and a heart attack was diagnosed. Over the next two days, he was intermittently agitated and required anti-anxiety medication and morphine for comfort. Delirium worsened, forcing caregivers to apply restraints to prevent him from dislodging his breathing tube. Bilateral pneumonia was treated with high dose antibiotics and his blood pressure was maintained with cardiac pressor medications.

Mrs. Jessop was emotionally distraught. She spent many hours at her husband's bedside, but said little to the nurses or staff. Every day various specialists explained her husband's condition from their respective perspectives, encouraging her to be hopeful. They emphasized that he was critically ill, but they never explicitly said he might die. Mrs. Jessop found it difficult to determine who was in charge of her husband's care and to know how to interpret seemingly conflicting messages.

Mr. Jessop, in his second week in the ICU, remained somnolent and intermittently agitated. Standing beside her mother, Mr. Jessop's daugh-

ter said to the cardiologist as he made morning rounds, "This is wrong. My father would not want to be here like this." The cardiologist was surprised by the comment and felt criticized. He replied that removing the breathing tube or untying Mr. Jessop "would kill him." To this Mr. Jessop's daughter replied, "It feels like you are torturing him. Won't you please just allow my father to die?"

Mr. Jessop's pulmonologist felt uncomfortable about withdrawing mechanical ventilation, fearing that it would cause suffering and might be perceived as euthanasia. He asked for an ethics committee evaluation. Before his case could be considered, however, Mr. Jessop developed ventricular fibrillation. Resuscitation efforts failed and he was pronounced dead.

### CRISIS AT THE END OF LIFE

Mr. Jessop's case epitomizes an all-too-common predicament. Evidence suggests that many Americans die in physical distress, while receiving aggressive medical treatment that may not be consistent with their preferences for care and is not

justified by its likely benefit. This state of affairs is amply documented in published research and apparent in poignant accounts of many who have endured the loss of a loved one.

In 1995 results were released of a study, commissioned by the Robert Wood Johnson Foundation, which had involved 9,000 critically ill patients at five major U.S. medical centers. The findings of the \$28 million Study to Understand Prognosis and Preference for Outcomes and Risks of Treatment (SUPPORT) confirmed that a crisis exists in the way Americans are cared for at the end of life.<sup>1</sup> Many patients die in ICUs, often in pain and often without their preferences for care having been elicited or honored. Despite the expansion in home care and the growth of hospice in the past two decades, little progress has been made in the way a majority of Americans die.

Recent studies indicate an incongruity between what seriously ill people feel is most important about health care and what the current health care system provides. In a study involving qualitative analysis of interviews with patients, recently bereaved family members, and experienced clinicians, researchers found that seriously ill patients and their families value pain and symptom management, clear decision making, preparation for death and life completion, a sense of having contributed to others, and affirmation as a whole person.<sup>2</sup> Another qualitative study concluded that patients and families value clinicians who talk in honest, straightforward ways about their patients' conditions, and who can sensitively break bad news without shirking discussions about death.<sup>3</sup> Patients and family members want clinicians who encourage questions and are sensitive to when patients are ready to talk about death.

Although reasonable, these values and expectations are not consistently achieved. Indeed, two authorities in the field describe a health care system in which end-of-life discussions are not routine and care is frequently fragmented and often provided by multiple clinicians at multiple sites.<sup>4</sup> Contemporary physicians have fewer long-term relationships with patients, less time for communication, and do not feel charged with or compensated for discussions with patients' and families' about psychosocial and spiritual needs related to life completion.

Further complicating the misalignment between the needs of seriously ill patients and their families, on one hand, and current modes of health care delivery, on the other, are the reimbursement policies of Medicare and many insurance plans, which typically require patients to forgo life-prolonging care as a condition for receiving comprehensive palliative care. By statute and regulation, Medicare's hospice benefit is avail-

## CALL Care and "Promoting Excellence"

Between August 2001 and February 2003, 11 Catholic health care organizations involved in CALL Care, a nationwide project sponsored by Supportive Care of the Dying: A Coalition for Compassionate Care, Portland, OR, were Promoting Excellence demonstration sites and received funds from the Robert Wood Johnson Foundation.

For more on CALL Care, see Sylvia McSkimming, RN, PhD; Marla London; Carol Lieberman; and Ellen Geerling in "Improving Response to Life-Threatening Illness," *Health Progress*, January-February 2004, pp. 26-33, 56.

The participating CALL Care organizations were:

- **Good Samaritan Health Center of Merrill**, Merrill, WI
  - **Holy Cross Hospital**, Silver Spring, MD
  - **Mercy Rehabilitation and Care Center**, Roseburg, OR
  - **Our Lady of Lourdes Regional Medical Center**, Lafayette, LA
  - **Sacred Heart Medical Center, PeaceHealth-Oregon Region**, Eugene, OR
  - **Providence Hospitals and Medical Centers**, Southfield, MI
  - **St. John Neumann Nursing Home**, Philadelphia
  - **St. John's Regional Medical Center**, Joplin, MO
  - **St. Joseph Mercy-Oakland**, Pontiac, MI
  - **St. Mary's Hospital and Medical Center**, Grand Junction, CO
  - **Via Christi Regional Medical Center**, Wichita, KS
- SSM Cardinal Glennon Children's Hospital**, St. Louis, is currently a Promoting Excellence demonstration site.

able only to recipients who are judged to have a life expectancy of six or less months *and* are willing to forgo disease-modifying care. Although such eligibility criteria were reasonable when Congress enacted the Medicare hospice benefit in 1982, they are out of step with today's health care environment, in which patients with chronic illnesses may live for many months at high risk of dying, yet with acceptable quality of life. The line between treatments intended to prolong life and those intended to improve comfort and quality of life has blurred. The current dichotomy between life-prolonging and palliative care results in a *sequential* approach to care, whereas a *concurrent* approach would much better respond to the needs of seriously ill patients and families (see Figure 1).

Society's cultural fixation on cure and its relative inattention to comfort and quality of life—combined with third-party payer rules that impose an arbitrary either-or choice between “curative care” and palliative care—inadvertently add to the burden that patients with advanced illness may experience. A compelling need exists to realign health service delivery with the clinical realities and real needs of chronically ill patients and their families.

### A STRATEGIC RESPONSE

Since the results of the SUPPORT study were released, clinicians, health care administrators, health care consumers, funders, and payers have expressed keen interest in redesigning the health care system so that it can respond to the suffering experienced by patients with advanced, incurable illness. Recognizing this, the Robert Wood Johnson Foundation embarked on a strategic plan to improve care through the end of life. Employing a multifaceted approach that acknowledged the complexity of achieving cultural change and simultaneously targeted multiple leverage points, the foundation developed a broad quality-improvement strategy that includes efforts to elucidate clinical-practice standards and domains of quality for palliative care, measurement tools and methodologies applicable to these standards and domains, evaluation of performance and outcomes, training curricula, continuing education for clinicians that encompass the breadth of palliative care practice, and support for relevant certification and accreditation processes.<sup>5</sup> The foundation's strategy also includes support for research and development of demonstration projects to build and assess innovative models of care delivery. Public education to raise awareness of palliative care and end-of-life issues; to empower consumer and citizen advocacy; and to prompt needed changes in poli-

cy, reimbursement, and regulatory matters round out this strategy.

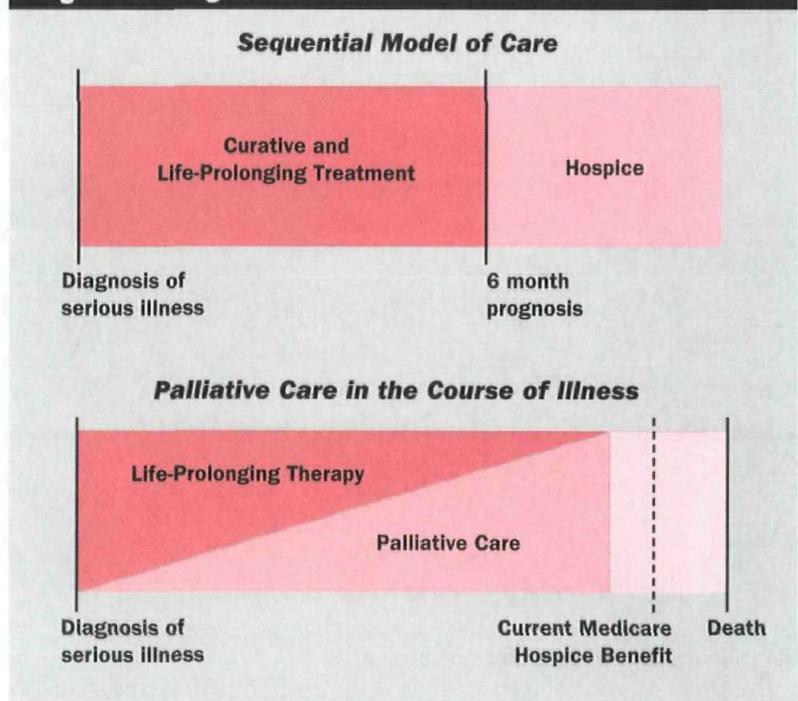
### PALLIATIVE CARE

At the heart of these strategic efforts is an unwavering belief that seriously ill patients and their family members deserve coordinated and continuous attention provided by a skilled team to their psychosocial and spiritual needs, as well as to their physical needs. This approach, which puts the patient and family (rather than providers or the reimbursement system), front and center is called *palliative care*. Palliative care is defined as interdisciplinary care for persons with life-threatening illness or injury that addresses physical, emotional, social, and spiritual needs and seeks to improve quality of life for the ill person and his or her family. Treatment and secondary prevention of symptoms and suffering and preservation of personal opportunity are hallmarks of palliative care.<sup>6</sup>

Palliative care includes a defined array of services that are provided to patients and families in an organized, cohesive manner. Hospice has traditionally been the primary means for delivering palliative care. However, because Medicare and many third-party payers limit hospice care to patients who have a terminal prognosis and who agree to treatment that is exclusively focused on comfort and quality of life, many seriously ill Americans decline to avail themselves of this benefit, or do so

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Figure 1: Integrated Models of End-of-Life Care



only after exhausting all potentially life-prolonging interventions. Prognostic uncertainty, distrust of the health care system—especially among disadvantaged ethnic groups—and an understandable desire to pursue potentially life-extending treatment further confound appropriate referral to and acceptance of hospice care.

Over the past decade, efforts have been under way to build on the comprehensive, holistic, patient- and family-centered care traditionally delivered by hospice by making such care available to everyone needing palliation, regardless of diagnosis, prognosis, age, socioeconomic status, or venue of care. Promoting Excellence in End-of-Life Care, a national initiative of the Robert Wood Johnson Foundation, is one such effort.

### PROMOTING EXCELLENCE

The Promoting Excellence program was launched in 1997 to support innovative health service delivery to identified patient populations and clinical settings in which hospice care was underutilized or unavailable. Setting the best hospice programs and care as “gold standards,” the program sought to extend palliative care “upstream” in the course of illness, concurrent with the provision of ongoing life-extending care. Local hospice programs were collaborating partners in many of the program’s demonstration projects, and most projects developed a continuum of services that included referral to hospice.

The 28 demonstration projects that were awarded Promoting Excellence grants represented a broad range of patient populations and contexts of care. They included four projects based in university cancer centers; two in tertiary care pediatric hospitals; a set of regional dialysis clinics; several hospice and home health agencies in highly pene-

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1997.

trated managed care environments; and projects in rural and frontier communities, inner cities, nursing homes, dementia programs, and even (in four states) in penitentiaries.

Creating prototypical models of care was chosen as the most direct means of determining whether palliative care could be delivered to patient populations within challenging contexts of care. Demonstration projects provide tangible examples of what is—and is not—feasible and how highly it is valued. The models developed by Promoting Excellence grantees represent applied research, the translation of theory into practice. Whenever possible, clinical tools, curricula, and programmatic resources were crafted to be adoptable, or adaptable, in similar settings. If successful, such prototypes have the potential to stimulate improvement well beyond local systems and communities, raising collective expectations and challenging administrators, health planners, and public policymakers to aim higher than they otherwise might.

### COMMON PROGRAMMATIC THREADS

Corresponding to the diversity of settings, illnesses, and patient populations served, Promoting Excellence projects are each unique, with operational strategies and patterns of service that respond to the needs of local stakeholders—patients, families, clinicians, health system managers, administrators, and policymakers—fitting their particular health systems and communities. Within this diversity, however, the programs share common elements of care, component services, and qualities (see **Box**).

Each program strives to deliver state-of-the-art clinical care to both patients and their families and is committed to respecting the cultural, ethnic, religious, and personal values of those they serve. Each program emphasizes clear communication with patients and families through clinical protocols, education, and quality improvement. Each has an interdisciplinary team that creates multifaceted, highly individualized plans of care reflecting the patient’s and family’s values and preferences for care. Crisis prevention and early crisis management is a common component of practice and care planning. Care plans are frequently updated to reflect the changing condition of the patient and family.

Recognizing the importance of continuity of care, the Promoting Excellence grantees have provided case management in every program, but in a diversity of ways. Most often, a specified nurse or social worker serves as a “care coordinator.” The responsibilities of this key position include maintaining updated knowledge about the patient’s and family’s status; overseeing implementation of

### Typical Palliative Care Services

Palliative care services usually include:

- Ongoing communication and review of goals of care
- Advance care planning
- Formal symptom assessment and treatment
- Care coordination
- Spiritual care and attention to psychosocial needs
- Anticipatory guidance related to adaptation to illness and issues of life completion and life closure
- Crisis prevention and early crisis management
- Bereavement support
- Around-the-clock availability of a clinician knowledgeable about the patient and family

the plan of care; acting as an advocate for the patient and his or her family and assisting them in obtaining and coordinating services and appointments; and maintaining communication among patients, families, and the health care team.

In building innovative models, the grantees confronted challenges that, once overcome, led to strong, successful and sustainable programs for delivering care (see **Box**, p. x). Lessons learned by the grantees suggest that palliative care programs can align with and advance the institution's mission.

To succeed, programs must begin with a manageable scope, allowing nascent initiatives to achieve early successes and earn support and commitment from recognized leaders in both clinical and administrative realms. Palliative care teams are more readily integrated into the institution's clinical practice when they are able to reduce the burden experienced by time-pressured clinicians who are often untrained to delve into patients' and families' psychosocial needs and discuss ramifications of the patients' life-compromising illnesses. Successful interdisciplinary teams embed palliative care practices into routine operations and have authority to carry out their recommendations and interventions for patient care. Teams earn the confidence of colleagues by skillfully and reliably caring for difficult, complex cases.

In addition to focusing on clinical aspects of integrating palliative care and cure-oriented treatment, sustainable programs also develop long-range business and communications plans to ensure that all stakeholders receive targeted, cohesive messages about the availability of palliative care services and their benefits, and that these messages are augmented by supporting data that demonstrates efficacy.

### PROMISING RESULTS IN LOS ANGELES

The Promoting Excellence initiative supported the creation of new models of care delivery, requiring that grantees develop sound evaluation plans to measure the impact of their innovative work. Evaluation focused on demonstrating the *feasibility* of the delivery model, its *acceptability* to a diverse mix of stakeholders, and its *sustainability*. As far as was possible, grantees also evaluated:

- Whether access to palliative care improved
- The impact of the initiative's intervention on quality of care, as perceived by patients, families, and clinicians
- The financial ramifications of providing palliative care concurrently with life-prolonging care

Most Promoting Excellence projects have completed their grant-funded work and continue to analyze data to gauge the impact of providing comprehensive palliative care simultaneously with potentially life-prolonging treatments. Their pre-

liminary data on access, quality, and cost is promising. A brief look at one project may serve as an illustration. The Pathways of Caring program, sponsored by the U.S. Department of

## 10 Essential Ingredients for Building Successful Palliative Care Programs

### To succeed, a palliative care program should have:

- A well defined vision that
- Advances the institution's mission
- Encompasses a comprehensive definition of palliative care

### A well-planned implementation strategy that is

- Manageable in scope
- Consistent with available human and financial resources

### Unwavering support from clinical and administrative leaders willing to

- Champion the program
- Help secure operational resources

### Ongoing efforts to bridge the differences between palliative and acute care clinical cultures that

- Entails learning on both sides
- Integrates experienced staff with diverse expertise, including psychosocial and spiritual care

### A focus on making "the right way the easy way" by

- Responding to workday needs of time-pressured clinicians and management
- Redesigning operations to embed and trigger palliative practices in daily routines

### Ongoing education, support, and attention to team building for clinicians and system personnel to

- Ease adoption of innovation
- Strengthen clinical interventions

### An assurance that palliative care teams have authority to carry out their clinical recommendations and interventions for patient care and have "safe havens" for the discussion of problems and ideas

### Attention to diverse ethnic and religious cultures of individual patients and families through

- Sensitivity to the uniqueness of individuals and their preferences
- Careful selection of language to convey program elements

### Targeted data collection focusing on

- Increased access to palliative care
- Improved quality of care
- Resource utilization and cost
- Patient/family/clinician satisfaction

### A communications strategy for succinctly presenting relevant data to stakeholders

Veterans Affairs' Greater Los Angeles Healthcare System (GLA), is unique. However, the experience and findings of this project exemplify the programmatic experience of others.

Pathways of Caring was committed to providing, for patients with advanced life-limiting illnesses, what the project's clinician-researchers termed the "seemingly contradictory approaches" of side-by-side disease-modifying treatment and palliative care focused on increasing comfort and quality of life. The patients involved were specific groups of veterans, including those with lung cancer, advanced congestive heart failure, and chronic obstruction pulmonary disease.

The Pathways researchers began by identifying patients in GLA's hospital, clinic rolls, and medical records who had poor prognoses and were likely to benefit from comprehensive symptom management. The project's goals included ensuring relative comfort for patients, coordinating care through the course of illness, and expanding access to home care and hospice. A nurse case manager educated patients and their families regarding decision making and self-management of symptoms. The nurse also provided continuity of care, serving as the hub of an interdisciplinary team that included a social worker, chaplain, dietician, and physician, all of whom worked together to meet each patient's and family's needs.

Preliminary data on 54 participants who died while enrolled in the Pathways program, compared with a retrospectively matched control group of patients who did not receive the palliative intervention, show dramatic differences. Available evidence indicates improvements in the proportion of cases with documented goals of care and completed advance directives. Forty-three percent of Pathways patients were able to die at home, compared to just 7 percent of matched control patients. Forty-five percent of

A steady rise in referrals and caseload evidenced the program's feasibility.

Pathways patients died in a hospital or long-term care facility, compared to 68 percent of control patients.

The Pathways program averaged 3.5 hospital days per patient during the final month of life, compared with 8.2 days for the control group. More striking still, the patients who died while served by Pathways spent an average of just 0.4 days in an intensive care unit during the last month of life, compared with 4.5 days for those in the group not served. Pathways patients on average also spent far less time on mechanical ventilators in their final month, just 0.1 days per patient in the group served versus 3.5 days in the comparison group.

The program's ability to better manage its patients with life-threatening illnesses in more appropriate and cost-effective settings has important financial ramifications, with overall savings of 45 percent on the cost of care in the final month of life (see Table 1).

The feasibility of this service delivery model and its acceptance by veterans, their families, and clinicians was clearly evidenced by the appreciation expressed and the steady rise in referrals and caseload. The ability of the Pathways team to document the program's success, including its salutary impact on the system's efficiency and use of health resources, provided a convincing argument for sustaining the program beyond the grant's duration. In fact, the Pathways program is currently being expanded, with increases in the number of case management nurses and palliative care staff physicians, expansion and further integration of the palliative care consultation team, and formalization of an outpatient palliative care clinic. Further description of Pathways of Caring, as well as of other Promoting Excellence grant programs and resources, including two monographs, "Financial Implications of Promoting Excellence in End-of-Life Care" and "Living and Dying Well with Cancer," can be found at [www.promotingexcellence.org](http://www.promotingexcellence.org). A special series of articles in the *Journal of Palliative Medicine* describes Promoting Excellence programs and preliminary findings.<sup>7</sup>

#### MR. JESSOP AGAIN

Although it is impossible to say with certainty what the final days of life would have been like for Mr. Jessop, had he been a patient in a program like Pathways of Caring, some things would undoubtedly have been different. Because of the severity of his chronic illness, Mr. Jessop would have been identified during a clinic visit or during one of his previous emergency hospitalizations as someone who would benefit from palliative care. A palliative care coordinator would have assessed

**Table 1: Cost Per Patient in the Final Month of Life**

	Pathways of Caring	Control Group
Number	54	28
Inpatient costs, mean*	\$ 4,416	\$15,506
Nursing home care unit costs, mean	\$ 2,428	\$ 1,424
ICU costs, mean	\$ 250	\$ 4,871
Outpatient costs, mean	\$ 3,069	\$ 1,923
Total costs, mean	\$10,248	\$18,853

\*Does not include long-term care facility costs listed separately.

Source: Department of Veterans Affairs, Greater Los Angeles Healthcare System

the immediate needs of both Mr. Jessop and his family and provided education about advanced congestive heart failure and its unpredictable trajectory. Mr. Jessop's family situation, values, religious or spiritual concerns, and wishes would have been explored, and he would have been guided to put his preferences for care in writing within an advance directive. A team of clinicians, including his primary physician and palliative care coordinator, would have contributed to a multifaceted plan of care and been available to manage the crises.

If Mr. Jessop had been in a palliative care program when the latest exacerbation of his illness occurred, events might have unfolded quite differently than they did. With a plan of care already in place and the availability of a familiar nurse coordinator to assess and guide, Mr. Jessop and his family would have reported his symptoms to the nurse with whom they were familiar. After assessing his symptoms by phone the nurse would have instructed him to take an extra dose of diuretic or made a home visit to further evaluate, adjust his medications, and plan careful follow-up. It's possible the crisis would have been averted—and his life prolonged.

If his condition had worsened, Mr. Jessop and his family could have made an informed decision whether to go to the hospital or be cared for at home. At the least, his desire to die peacefully, without an extended traumatic stint in an ICU, could have been known and honored.

While the number of patients studied in the Pathways project is small, the findings show trends that were substantiated by other Promoting Excellence projects. Early results from these prototypes suggest that concurrent palliative and cure-oriented care is clinically effective and associated with systems efficiencies and no increase in total health care resources; in fact, they indicate that fewer resources were needed for patients in palliative care than for those who were not.

### BUILDING ON POSITIVE RESULTS

The Institute of Medicine's landmark 1997 report, *Approaching Death: Improving Care at the End of Life*, recognized an urgent need to improve care through the end of life and called for significant improvements in clinical education, health systems design, and service delivery, as well as for changes in health care financing, outcomes measurement, quality improvement, and oversight.<sup>8</sup> In the era of patient-centered care it is no longer acceptable for our health care system to do what is expedient for institutions and providers. Patients with advanced, incurable conditions and their loved ones must be able to expect clear communication, shared decision making, effective

management of symptoms, continuity of care, prevention of or early response to crises, and support for families in their caregiving and in their grief. Although preliminary, the early programmatic and clinical findings of Promoting Excellence projects have clearly shown that these reasonable expectations are achievable.

Most of these projects are continuing beyond their period of grant support. They have proven their feasibility and efficiency within their local health systems and have been highly valued by patients, families, and providers alike. Collectively, these prototypes have demonstrated that it is possible to align health services to meet the needs of seriously ill patients and their families, notably improve outcomes of care, while remaining fiscally responsible for the financial well-being of the institutions involved. The challenge now is to build upon this promising work through population-based demonstration projects and studies. □

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### NOTES

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6. Standards and Accreditation Committee, *A Pathway for Patients and Families Facing Terminal Disease*, National Hospice Organization, Washington, DC, 1997.
7. See, for example, M. Bakitas, M. Stevens, T. Ahles, et al., "Project ENABLE: A Palliative Care Demonstration Project for Advanced Cancer Patients in Three Settings," and M. Ratcliff and E. Craig, "The GRACE Project: Giving End-of-Life Care in Corrections 1998-2001," both in the *Journal of Palliative Medicine*, vol. 7, no. 2, April 2004. For the Pathways of Caring program, see K. Rosenfeld and J. Rasmussen, "Palliative Care Management: A Veterans Administration Demonstration Project," *Journal of Palliative Medicine*, vol. 6, no. 5, October 2003, pp. 832-839.
8. M. J. Field and C. K. Cassel, eds., *Approaching Death: Improving Care at the End of Life*, National Academies Press, Washington, DC, 1997.