

## Increased Access to Palliative Care and Hospice Services: Opportunities to Improve Value in Health Care

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**Context:** A small proportion of patients with serious illness or multiple chronic conditions account for the majority of health care spending. Despite the high cost, evidence demonstrates that these patients receive health care of inadequate quality, characterized by fragmentation, overuse, medical errors, and poor quality of life.

**Methods:** This article examines data demonstrating the impact of the U.S. health care system on clinical care outcomes and costs for the sickest and most vulnerable patients. It also defines palliative care and hospice, synthesizes studies of the outcomes of palliative care and hospice services, reviews variables predicting access to palliative care and hospice services, and identifies those policy priorities necessary to strengthen access to high-quality palliative care.

**Findings:** Palliative care and hospice services improve patient-centered outcomes such as pain, depression, and other symptoms; patient and family satisfaction; and the receipt of care in the place that the patient chooses. Some data suggest that, compared with the usual care, palliative care prolongs life. By helping patients get the care they need to avoid unnecessary emergency department and hospital stays and shifting the locus of care to the home or community, palliative care and hospice reduce health care spending for America's sickest and most costly patient populations.

**Conclusions:** Policies focused on enhancing the palliative care workforce, investing in the field's science base, and increasing the availability of services in U.S. hospitals and nursing homes are needed to ensure equitable access to optimal care for seriously ill patients and those with multiple chronic conditions.

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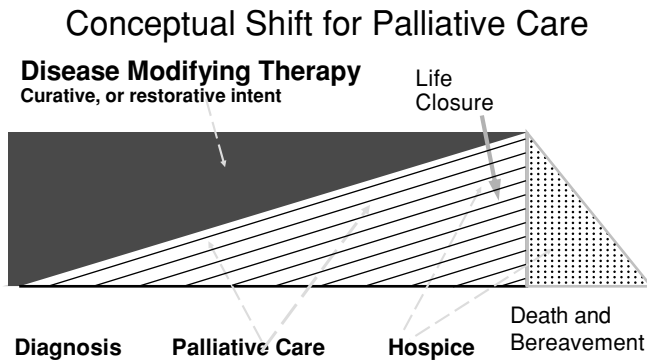
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**I**N ITS 2008 REPORT, *NATIONAL PRIORITIES AND GOALS—ALIGNING OUR Efforts to Transform America's Healthcare* (NQF 2009; Partnership 2008), the National Priorities Partnership (NPP) identified six national priorities that, if addressed, would significantly improve the quality of health care delivered to Americans. The NPP is a consortium of forty-eight major U.S. health care organizations working with the National Quality Forum (NQF) to identify and advance those quality priorities most likely to improve health care in the near future (NQF 2009). In recognition of evidence of poor health care quality despite high expenditures for patients with multiple chronic conditions, functional impairment, and serious and life-threatening illness, the NPP identified palliative care as one of its six priority areas, reflecting the impact of both palliative care and hospice services on improving key patient-centered quality and utilization outcomes. This article was developed as a background piece for a meeting of the National Priority Partners Palliative and End of Life Care work group with the aim of identifying the steps necessary to match medical treatment to patient and family goals through improved access to quality palliative care and hospice services.

## Background

### *What Is Palliative Care?*

Palliative care focuses on achieving the best-possible quality of life for patients and their family caregivers, based on patient and family needs and goals and independent of prognosis. Interdisciplinary palliative care teams assess and treat symptoms, support decision making and help match treatments to informed patient and family goals, mobilize practical aid for patients and their family caregivers, identify community resources to ensure a safe and secure living environment, and promote collaborative and seamless models of care across a range of care settings (i.e., hospital, home, and nursing home).



NHWG: Adapted from work of the Canadian Palliative Care Association and Frank Ferris, MD.

FIGURE 1. National Consensus Project for Quality Palliative Care, 2004.

In the United States, palliative care is provided both within and outside hospice programs. Palliative care outside hospice is offered independent of the patient's prognosis and simultaneously with life-prolonging and curative therapies for persons living with serious, complex, and life-threatening illness (see Figure 1). Ideally, palliative care should be initiated concurrently with a diagnosis of a serious illness and at the same time as curative or disease-modifying treatments, given the near universal occurrence of patient and family distress and their need for information and support in establishing achievable goals for the patient's medical care. Unlike hospice, palliative care may be primary, secondary, or tertiary (von Gunten 2002). Primary palliative care should be part of what all treating clinicians provide their patients (such as pain and symptom management, discussions about advance care planning); secondary palliative care is offered when the treating physician refers to specialist-level palliative care experts for unusually complex or difficult problems; and tertiary palliative care includes research and teaching in addition to specialist-level palliative care expertise.

U.S. hospice services are delivered in a model established by statute in Medicare and followed by most other insurers. The Medicare Hospice Benefit is largely restricted to patients with a prognosis of living for six months or less, if the disease follows its natural course, who agree to forgo therapies with curative intent. Hospice is designed to provide comprehensive, interdisciplinary, team-based palliative care, mostly in a place the patient calls home, for dying patients with an identifiably

short prognosis. Hospice care is appropriate when patients and their families decide to forgo curative therapies in order to focus on maximizing comfort and quality of life, when curative treatments are no longer beneficial, when the burdens of these treatments outweigh their benefits, or when patients are entering the last weeks or months of life. Hospice services are highly standardized by the Medicare Conditions of Participation, although the intensity and nature of those services are determined by patient and family need and stage of illness (e.g., hospice services are typically most intensive in the last days of life when symptoms and family distress often peak) (Morrison and Meier 2004; National Consensus Project for Quality Palliative Care 2004; NQF 2006). Hospice supports the family caregiver(s) throughout the care process and provides bereavement services to family members after the patient's death.

It is important to note that the prognosis-based distinction between palliative care (eligibility based on need, no prognostic restriction) and hospice (eligibility based on a prognosis of living less than six months) is unique to the United States, whereas in other countries the terms *palliative care* and *hospice* are largely synonymous. In fact, it was the need for palliative care for those patients not meeting the hospice eligibility requirement for a prognosis of living six months or less (i.e., those with serious or chronic illness who are not dying soon) that led to the recent rapid growth in hospital palliative care teams in the United States.

### *Why Do We Need Palliative Care?*

Studies demonstrate that patients with a serious illness and their families receive poor-quality medical care, characterized by untreated symptoms, unmet psychosocial and personal care needs, a great burden for the caregiver, and low patient and family satisfaction (Foundation 2005; Teno et al. 2004; Thorpe and Howard 2006). Of the \$491 billion spent by Medicare in 2009, 27 percent (\$132.5 billion) was spent on acute care (hospital) services and a small proportion—10 percent—of the sickest Medicare beneficiaries accounted for about 57 percent of total program spending, which was more than \$44,220 per capita per year (MedPAC 2010a). The costliest beneficiaries include those using hospital services, those with multiple chronic conditions or functional dependencies, those with dual eligibility for Medicare and Medicaid,

and those in their last year of life—all of whom are the appropriate target population for palliative care and, when eligible, hospice services (Office of Assistant Secretary for Planning and Evaluation et al. 2010).

### *Essential Elements of Quality Palliative Care and Hospice*

As outlined by the National Quality Forum (NQF 2006) and the National Consensus Project for Quality Palliative Care (2004), the essential structural elements of palliative care are the following:

- Interdisciplinary team of clinical staff (physician, nurse, social worker, spiritual counselor, pharmacist, aide, volunteers).
- Staffing ratios determined by the nature and size of population to be served.
- Staff trained, credentialed, and/or certified in palliative care.
- Access and responsiveness twenty-four hours per day, seven days per week.

The NQF Guidelines (NQF 2006) include thirty-eight preferred structure and quality practices that have been used to develop quality metrics for hospital palliative care services in the United States (Arnold and Weissman 2004; Weissman and Meier 2008, 2009; Weissman, Meier, and Spragens 2008; Weissman, Morrison, and Meier 2010). Examples of preferred practice measures are the determination and documentation of patient and family goals for care through advance care planning using, for example, the Medical or Physician Orders for Life-Sustaining Treatment (also known as MOLST or POLST, see [www.polst.org](http://www.polst.org)) (Hickman et al. 2010; Meier and Beresford 2009) or the Respecting Choices (Hammes, Rooney, and Gundrum 2010) paradigm ([www.respectingchoices.org](http://www.respectingchoices.org)), both of which have been shown to increase the likelihood that the care actually received is concordant with the patient's goals.

### *How Do Palliative Care and Hospice Improve Health Care Value?*

Value in health care is defined as the ratio of quality to cost. Value can be improved by improving quality, reducing cost, or, preferably,

both. The seriously ill and those with multiple chronic conditions and functional impairment constitute about 10 percent of all patients in the United States but account for well over half of the nation's health care costs (Office of Assistant Secretary for Planning and Evaluation et al. 2010). Palliative care programs targeting this patient population in hospitals are a rapidly diffusing innovation (Goldsmith et al. 2008) and have been shown to increase value by both improving quality and reducing costs of care for the sickest and most complex patients (Anderson and Horvath 2002; Back, Li, and Sales 2005; Brumley et al. 2007; Elsayem et al. 2004; Kelley and Meier 2010; Morrison et al. 2008; Penrod et al. 2006; Smith et al. 2003; Temel et al. 2010; Teno et al. 2004; Wright et al. 2008; Zhang et al. 2009).

Similarly, Medicare-certified hospices serve more than 1.5 million dying Americans each year (about 41% of all Medicare deaths in 2009) (MedPAC 2010c; NHPCO 2010b), and hospice care is also associated with demonstrable improvements in quality and reductions in total health care spending (Christakis and Iwashyna 2003; Connor et al. 2007; Lorenz, Lynn, and Dy 2006; Morrison and Meier 2004; Taylor Jr. et al. 2007). Palliative care and hospice programs, therefore, are an important approach to improving health care value through their ability to both improve quality of care and reduce the costs facing our health care system.

### *How Do Palliative Care and Hospice Improve Quality of Care?*

Palliative care and hospice programs demonstrably improve physical and psychosocial symptoms, family caregiver well-being, bereavement outcomes, and patient, family, and physician satisfaction (Casarett et al. 2008; Cassel et al. 2002; Elsayem et al. 2004; Fallowfield and Jenkins 2004; Fellowes, Wilkinson, and Moore 2004; Jordhoy et al. 2000, 2001; Lilly et al. 2000; Manfredi et al. 2000; Nilsson et al. 2009; Rabow et al. 2003; Ringdal, Jordhoy, and Kaasa 2002; Temel et al. 2010; Teno et al. 2004; Wright et al. 2008, 2010; Zhang et al. 2009). These objectives are achieved through care provided by interdisciplinary teams of physicians, nurses, social workers, spiritual counselors, pharmacists, aides, and additional personnel as needed (physical therapists, psychologists, and others). Palliative care and hospice teams identify and rapidly

treat distressing symptoms that have been independently shown to increase medical complications and hospitalization (Jordhoy et al. 2000; Manfredi et al. 2000; Morrison et al. 2009). Palliative care and hospice teams meet often with patients and their families to establish appropriate and realistic goals, support families in crisis, and plan for safe transitions out of hospitals to more supportive settings (home care, home hospice, nursing home care with hospice, or inpatient hospice care). Communication regarding the patient's prognosis and goals by a dedicated team with time and expertise leads to better-informed decision making, clarity of the care plan, and consistent follow-through. Such discussions at family meetings lead to lower costs and a lighter family burden (Wright et al. 2008, 2010) and improve family satisfaction and bereavement outcomes (Wright et al. 2008; Zhang et al. 2009).

Finally, and contrary to widely held assumptions, several recent studies have demonstrated that both palliative care and hospice care may be associated with a significant *prolongation* of life for some patient populations (Bakitas et al. 2009; Connor et al. 2007; Pyenson et al. 2004; Temel et al. 2010). Research is necessary to confirm these findings and assess their generalizability. Conjectures accounting for the possibility that palliative care and hospice may prolong life include reduction in depression, which is an independent predictor of mortality in multiple disease types; avoidance of the hazards of hospitalization and high-risk medical interventions; reduction in symptom burden; and improved support for family caregivers that permits patients to remain safely at home.

### *Impact of Palliative Care and Hospice on Health Care Spending*

Palliative care and hospice programs promote the delivery of coordinated, communicated, and patient-centered care by targeting the drivers of increased utilization of hospitals, specialists, and procedures. These drivers include financial incentives for quantity and fragmentation of care, lack of training in management of patients with complex or multiple chronic conditions, lack of a strong primary care infrastructure, and financial and structural disconnects between the acute and the postacute care settings for health care. By addressing pain and symptoms that might otherwise increase hospital complications and lengths of stay,

meeting with patients and families to establish clear care goals, tailoring treatments to those goals in consultation with the patients and their families, and developing comprehensive discharge plans, both hospital- and community-based palliative care and hospice programs can reduce costly and preventable hospitalizations, readmissions, and emergency department visits (Brody et al. 2010; Morrison et al. 2007, 2008; Siu et al. 2009; Smith et al. 2010; Temel et al. 2010). Patients are able to remain in their homes as a consequence of better family support, care coordination, and home care and hospice referrals; more hospital admissions go directly to the palliative care service or hospice program instead of a high-cost intensive care unit (ICU) bed; patients not benefiting from an ICU setting are transferred to more supportive settings; and nonbeneficial or harmful imaging, laboratory, specialty consultation, and procedures are avoided. Controlled trials in Europe (Higginson et al. 2002; Jordhoy et al. 2000) and the U.S. (Bakitas et al. 2009; Temel et al. 2010) and multisite studies in the United States suggest that the ability of palliative care and hospice programs to help patients avoid hospitalization can be substantial (Anderson and Horvath 2002; Back, Li, and Sales 2005; Brumley et al. 2007; Elsayem et al. 2004; Gomes et al. 2009; Harding et al. 2009; Morrison et al. 2008; Penrod et al. 2006; Smith and Cassel 2009; Smith et al. 2003; Taylor Jr. et al. 2007; Temel et al. 2010; Wright et al. 2008; Zhang et al. 2009).

Based on recent data (Morrison et al. 2008), the average per-patient per-admission net cost saved by hospital palliative care consultation is \$2,659. Approximately 2 percent of the 30 million annual hospitalizations in the United States end in death (AHRQ 2002). Assuming that most of these patients, plus the approximately 4 percent of patients who are discharged with serious and complex chronic illness, could benefit from palliative care services, palliative care programs should be serving approximately 6 percent of all hospital discharges (including patients who die). At present (2009 data), palliative care programs have been established at more than 60 percent of U.S. hospitals with more than fifty beds (CAPC 2010; Goldsmith et al. 2008) and affect approximately 1.5 percent of all discharges. Palliative care is estimated to save \$1.2 billion per year under the current penetration of services (to approximately 1.5 percent of all hospital discharges at 1,500 U.S. hospitals). This figure would increase to approximately \$4 billion per year if capacity were expanded to meet the needs of 6 percent of hospital discharges at



90 percent of all U.S. hospitals with more than fifty beds (Morrison, Meier, and Carlson 2011; Morrison et al. 2008; Siu et al. 2009).

Hospice care also reduces total health care costs for the majority of Medicare beneficiaries receiving it (Taylor 2009; Taylor Jr. et al. 2007). Using propensity score analysis to control for selection bias, an estimated \$2,300 is saved per hospice beneficiary on average, compared with similar patients not receiving hospice services. Extrapolating this average savings across the number of hospice patients served each year yields an overall savings of more than \$3.5 billion a year (1,560,000 patients  $\times$  \$2,300 = \$3.5 billion). The maximum savings was reached with a length of hospice use of approximately seven weeks, leading to reduced Medicare costs of \$7,000 for cancer patients and \$3,500 for others. The savings attributed to hospice patients persisted for 233 days of hospice care for cancer patients and 154 days of care for noncancer patients (Taylor Jr. et al. 2007). In addition, recent analyses have found that the costs of care for patients with cancer who disenrolled from hospice (disenrollment because of family exhaustion, symptom crises, or a need/desire for disease-directed treatments not covered under hospice) were nearly five times higher than for patients who remained with hospice. Patients who disenroll from hospice are far more likely than those who do not to use emergency department care and be hospitalized (Carlson et al. 2010).

Although studies generally have found that Medicare spending for hospice enrollees across settings is less than that for nonenrollees in the last several months before death, these savings diminish as hospice stays increase in length beyond 180 days (MedPAC 2008). The rise in access to hospice in long-term care settings has resulted in a rise in average (but not median) length of stay, primarily because of the growth in the number of very long-stay beneficiaries. Since hospice care is paid per diem, these long stays, along with the rising number of chronically ill Americans receiving hospice, have resulted in a quadrupling of government expenditures on hospice in the last eight years (MedPAC 2010c). Despite data pointing to overall Medicare savings associated with the use of hospice (Taylor Jr. et al. 2007), the recent growth in spending on hospice has led to ongoing government review by both the Medicare Payment Advisory Commission (MedPAC 2009; MedPAC 2010b) and the Department of Health and Human Services, as required in the Affordable Care Act of 2010 of the appropriate use of the Medicare Hospice Benefit. Concerns about the overuse of hospice focus on

Medicare beneficiaries with multiple chronic conditions and functional impairment who are not (imminently) dying and may survive beyond the initial six-month prognostic eligibility criterion set in statute (MedPAC 2010c).

### *What Do We Know about Measuring the Quality of Palliative Care?*

Information about the quality of palliative care and hospice programs is limited, but both the United States and other nations are investing in outcomes measures for quality improvement and public reporting (Anderson and Squires 2010; Currow et al. 2008). The NQF Framework and Preferred Practices (NQF 2006) include a number of relevant structure and process measures, but their correlation with relevant outcomes (symptom burden, caregiver burden, satisfaction, transitions, cost) is not known. Investigators at Brown University, along with the National Hospice and Palliative Care Organization (NHPCO), developed a survey measuring the postdeath hospice family evaluation of care (the Family Evaluation of Hospice Care or FEHC) (Teno et al. 2004), which has been endorsed by the NQF (NQF 2010). This voluntary survey measures the quality of hospice interventions directed toward the family as well as the family's perspective of the quality of care received by the patient. Individual hospice programs use the results of these NHPCO-administered surveys to improve their performance; they are not yet mandatory or publicly reported. While the perspective of the family is obviously a central component of quality, it may not fully reflect the patient's actual experience. For example, in studies that compare family and patient ratings of symptom intensity, families rate pain higher than patients themselves do, and patients rate family distress higher than family members do (Heyland et al. 2010; Rothen, Stricker, and Heyland 2010). Given these patients' advanced stage of illness, there are inherent difficulties in fashioning an empirical tool that is feasible, actionable, and patient centered to directly assess the patients' perceptions of hospice or palliative care. The Center for Medicare and Medicaid Services (CMS) of the U.S. Department of Health and Human Services does not currently require quality reporting from hospice, unlike other major Medicare provider groups (nursing homes, rehabilitation facilities, hospitals, certified home health agencies), although a Quality Assessment

and Performance Improvement (QAPI) program (CMS 2003) has been required as a hospice condition of participation in Medicare since 2008.

The 2010 Affordable Care Act (PL 111–148 section 3004), however, requires hospice to report to CMS on quality measures or face a 2 percent reduction in payments. Measures are to be endorsed by a “quality measure consensus-based entity” and must be published no later than October 1, 2012, for reporting to CMS beginning October 1, 2013. Through contracts with its state-based quality improvement organizations, CMS has initiated several projects to develop and field-test a series of hospice and palliative care measures (PEACE Project) (MedPAC 2010c), as both stand-alone measures and part of the validation of the CARE instrument (Continuity Assessment Record and Evaluation), a uniform cross-setting quality instrument developed by CMS. A new NQF call for hospice and palliative care measures was released in April 2011 under a contract from CMS as required by the Affordable Care Act (H.R. 3590 section 3004) (NQF 2011).

As with hospice, palliative care programs currently have no external quality-reporting requirements. The American Hospital Association’s annual survey contains a yes/no question on presence of a hospital palliative care program but does not ask for further information. The Center to Advance Palliative Care (CAPC) launched a program registry in 2009 for voluntary reporting on palliative care structure and process measures derived from the NQF Framework and Preferred Practices (<https://registry.capc.org/>; NQF 2006). Although data from the registry are not currently publicly available, they are promised in 2012, assuming there are enough registrants to allow valid comparison data. A series of consensus guidelines on structure and process measures for hospital consultation and inpatient-unit programs, derived from the NQF Framework, were developed and published by the Center to Advance Palliative Care (Weissman and Meier 2008, 2009; Weissman, Meier, and Spragens 2008; Weissman, Morrison, and Meier 2010) between 2008 and 2010, but they have been neither field-tested nor validated against patient level and efficiency outcomes. The U.S. Department of Veterans Affairs developed measures that evaluate the incidence of discussions on goals, chaplain visits, and advance directives. These measures then are used to evaluate palliative care teams in VA hospitals (Casarett et al. 2010; Lu et al. 2010). Importantly, The Joint Commission (TJC), which accredits most hospitals in the United States, created and field-tested a voluntary certificate program derived from the NQF Framework

for palliative care (NQF 2006), which it plans to release in September 2011 (TJC 2011).

Standardized empirical quality metrics that can be used for either internal or external quality-reporting and pay-for-performance methods are needed. As with other clinical outcome measures, quality metrics for palliative care and hospice should be able to demonstrate a clear link between structure and process and the relevant clinical and patient-centered outcomes, and the measures should represent areas that providers can improve.

## Barriers to Palliative Care and Hospice

The primary barriers to receiving quality palliative care and hospice are variability in access by geographic and other characteristics; an inadequate workforce and workforce pipeline to meet the needs of patients and their families; the need for an adequate research evidence base to guide and measure the quality of care; and the lack of public knowledge of, and demand for, the benefits of palliative care and hospice.

### *Access to Palliative Care and Hospice*

Until recently, palliative care services were typically available only to patients enrolled in hospice (National Consensus Project for Quality Palliative Care 2004). Now, however, palliative care programs are found increasingly in hospitals—a main site of care for the seriously ill and, on average, the site of death for 50 percent of adults nationwide—as well as in other settings. In 2009, 62 percent of U.S. hospitals (with at least 50 beds) and 84 percent of hospitals with more than 300 beds reported having a palliative care program, which is an increase of 134 percent from 2000 (American Hospital Association 2009; CAPC 2010; Goldsmith et al. 2008).

The 47 percent growth in the number of hospice programs and the 74 percent increase in the number of persons served by hospice in the United States in the last ten years have been equally dramatic (MedPAC 2009, 2010c; NHPCO 2010b). In 2009 there were 3,400 programs (93% of which are Medicare certified) serving approximately 1.56 million Americans, primarily in their homes (56% of days),

nursing homes (29% of days), or assisted living facilities (10.9% of days). In 2009 more than 40 percent of Medicare decedents used hospice at some point in their care, an increase from 23 percent in 2000 (MedPAC 2010c; NHPCO 2010b). More than 80 percent of hospice beneficiaries are over age sixty-five, and more than one-third are over eighty-five. In tandem with the aging of the hospice and U.S. population, patterns of diagnosis have changed. Ten years ago the majority (53%) of hospice patients died from cancer, while by 2008 only 31 percent had cancer and 69 percent died from chronic debilitating diseases such as frailty, atherosclerotic and respiratory disease, and dementia, for whom the art and science of predicting prognosis is considerably more uncertain (MedPAC 2010c; NHPCO 2008). These shifts in diagnoses reflect a pattern of hospice utilization increasingly correlated with the leading causes of death (cancer accounts for fewer than 25% of deaths in the United States), suggesting that hospice providers are responding to the needs of Medicare beneficiaries.

Access to palliative care and hospice programs is highly variable across the country. For-profit, southern U.S., and small and safety-net hospitals (fewer than 100 beds) are less likely to report hospital palliative care programs (CAPC 2008, 2010), compared with not-for-profit hospitals, hospitals outside the South, and larger hospitals. Even in settings in which a palliative care team is available, there is a great deal of variability in the services to which patients have access, ranging, for example, from a half-time nurse to a full interdisciplinary palliative care team (MedPAC 2010c). The presence of an adequately staffed palliative care team by itself, however, does not ensure access to palliative care for patients in need of it. At most U.S. hospitals, referral requires a request for consultation from the attending physician. In turn, variability in physicians' practice patterns, awareness, and training is a major contributor to the variability of patients' access. In an effort to reduce variability in access to palliative care for patients in need, a recent proposal calling for universal patient screening for the need for palliative care carried out upon admission to hospital or nursing home and for outpatients living with serious or complex illnesses could improve access to palliative care by promoting and standardizing early recognition and intervention (Weissman and Meier 2011).

Access to hospice is also highly variable, received by a low of 6.7 percent of all deaths in Alaska, to a high of 44.7 percent in Arizona, based on 2006 data (Atlas 2006). Reasons for this variation in the

utilization of hospice are unclear, as they do not appear to be related to differences in availability of hospice capacity across the states. Tables 1 and 2 list approaches to standardizing access to quality palliative care.

### *Workforce*

An inadequate medical and nursing workforce with expertise in palliative care is one of the greatest barriers to access. A report commissioned by the Health Resources and Services Administration (HRSA) in 2002 projected significant shortfalls in the nation's number of palliative medicine specialists (Salsberg 2002) and called for a policy focused on increased education and training in palliative medicine across all clinical specialties serving patients with chronic and serious illness; expanded funding and reimbursement to attract young physicians into the field; and examination of the appropriate role of nonphysician professionals (such as nurse practitioners, clinical social workers, and physician assistants) in strengthening access to palliative care across health care settings. Another physician-specific workforce study commissioned by the American Academy of Hospice and Palliative Medicine in 2010 conservatively estimated a shortfall of at least 2,787 full-time physicians (or approximately 6,000 palliative medicine physicians, given the frequency of part-time participation in the field) (Lupu 2010). This estimate did not factor in the as yet unmet need for access to outpatient specialist-level palliative care, currently among the greatest barriers to access for chronically and seriously ill persons who are not in the hospital and are not eligible for hospice. Because the time and communication-intensive nature of palliative care precludes standard productivity measures based on the volume of patients seen, part of the difficulty in expanding workforce capacity is the lack of appropriate and standardized productivity and compensation models for palliative care physician and nurse practitioner services in both inpatient and outpatient settings.

This workforce shortage has also had an impact on the hospice community. Growth in the number of hospice programs (and patients served) has rapidly outstripped growth in the number of trained professionals. More recently, the CMS requirement of face-to-face visits by physicians or nurse practitioners in order to recertify a patient's continued prognostic eligibility for hospice services (MedPAC 2008, 2009, 2010c) has heightened the mismatch between workforce capacity and clinical need.

TABLE 1  
Options for Strengthening Access to Quality Palliative Care and Hospice

Stakeholder Category	Actions
Quality improvement organizations	<ol style="list-style-type: none"> <li>1. Identify and measure access to palliative care and hospice services as a key marker of quality across all settings.</li> <li>2. Encourage adherence to NQF preferred practices and (when available) certificate criteria as a means of ensuring quality and standardizing program operations across the country.</li> </ol>
Consumer organizations	<ol style="list-style-type: none"> <li>1. Increase consumer awareness, education, and access to palliative care and hospice program information through consumer articles and linking organizational websites to <a href="http://getpalliativecare.org">getpalliativecare.org</a> and <a href="http://palliatiivedoctors.org">palliatiivedoctors.org</a>.</li> <li>2. Identify special topics related to palliative care and hospice that are of interest to their constituency, strengthen editorial content and feature pieces, and support data collection by survey and focus-group techniques to aid in development of requests and recommendations.</li> <li>3. Establish an internal task force or committee to identify high-leverage activities. Where appropriate, support policy initiatives that will improve access and quality of palliative care and hospice, such as enhanced workforce, research funding, and regulatory requirements.</li> </ol>
Accreditation and certification organizations	<ol style="list-style-type: none"> <li>1. Promote palliative care certificate program to hospitals, home care, and long-term care settings.</li> <li>2. Exempt ACGME-approved palliative medicine fellowship training from the GME funding cap.</li> <li>3. Encourage adherence to NQF preferred practices and participation in palliative care certificate programs in the review process for hospitals. Review, recognize, and reward hospitals, home care, and long-term care settings that receive certification.</li> </ol>

*Continued*

TABLE 1—*Continued*

Stakeholder Category	Actions
Purchasers/businesses	4. Establish and promote standards for medical practice in a broad range of specialties for ABMS's new subspecialty certification in hospice and palliative medicine.
	5. Develop claims-based measure of competency in number of referrals to palliative care and hospice.
	6. Implement measures of use of services, including days in ED, ICU, and hospital at end of life and number of days in hospice care.
	7. Develop measures of institutional capacity for high-quality palliative care services.
	8. Develop composite measure of symptoms assessment (pain, dyspnea, constipation, health-related quality of life) that is harmonized across all settings.
	9. Develop a standard measure of hospital and nursing home mortality that distinguishes preventable deaths from expected deaths.
	10. Adapt Family Evaluation of Hospice Care (FEHC) survey to multiple settings.
	1. Require presence of a quality palliative care and hospice program as a condition of preferred provider status.
	2. Sponsor and encourage demonstration projects or pilots that support concurrent palliative care in hospital and home settings, including provision for collaboration with hospice providers.
	3. Increase employee awareness, education, and access to palliative care and hospice program information through company website and linking to <a href="http://nhpco.org">nhpco.org</a> , <a href="http://getpalliativecare.org">getpalliativecare.org</a> , and <a href="http://palliativedoctors.org">palliativedoctors.org</a> .
	4. Help employers educate employees and dependents on opportunities to choose high-quality palliative care and hospice (such as the work by the National Business Group on Health).



TABLE 1—*Continued*

Stakeholder Category	Actions
Payers	<p data-bbox="462 300 672 324">Payment for Services</p> <ol style="list-style-type: none"> <li data-bbox="477 331 965 413">1. Reimbursement for nonphysician interdisciplinary team members in the acute care setting.</li> <li data-bbox="477 420 965 531">2. Develop appropriate compensation by Medicare and private insurance to ensure provision of time-intensive expert palliative care of complex, seriously ill patients.</li> <li data-bbox="477 538 965 619">3. Develop a reimbursable code for family and goals of care conferences that do not require the patient's presence.</li> <li data-bbox="477 626 965 795">4. Provide pay-for-performance programs that reward hospitals offering palliative care consultation and/or hospice referral for patients with complex, multiple comorbidity and end-stage disease (measurable via claims and DRG data).</li> <li data-bbox="477 802 965 883">5. Delay changes in hospice reimbursement mechanisms until appropriate research on implications for access to care is completed.</li> <li data-bbox="477 890 965 972">6. Require access to quality palliative care and hospice programs as a condition of participation or licensure.</li> <li data-bbox="477 979 965 1060">7. Encourage and support cross-state consistency and enhancement of Medicaid coverage for palliative care and hospice.</li> <li data-bbox="477 1067 965 1208">8. Include palliative care and hospice as essential insurance benefits. Educate consumers to select plans covering palliative and hospice care and link sites to <a href="http://getpalliativecare.org">getpalliativecare.org</a>, <a href="http://palliativedoctors.org">palliativedoctors.org</a>, and <a href="http://nhpco.org">nhpco.org</a>.</li> <li data-bbox="477 1215 965 1355">9. Sponsor and encourage demonstrations or pilots that support concurrent palliative care activities in hospital, nursing home, and home settings, including provision for collaboration with hospice providers.</li> <li data-bbox="477 1362 965 1437">10. Include palliative care and hospice as a regular topic in all health plan quality committee meetings.</li> </ol>

*Continued*

TABLE 1—*Continued*

Stakeholder Category	Actions
Health professional organizations/ providers	Payment for Education
	11. Offer medical school loan forgiveness for physicians and advance practice nurses who seek subspecialty training in palliative medicine.
	12. Provide special cap-exempt graduate medical education (GME) funds to support GME for ACGME-accredited palliative medicine fellowship training programs.
	13. Increase GME/IME payments and hospital budgets for palliative medicine training programs for ACGME-accredited palliative medicine fellowship programs.
Research and workforce organizations	1. Develop a reimbursable code for family conferences that does not require the patient's presence.
	2. Develop a CPT code for palliative care associated with reimbursement commensurate with the time intensity, team approach, and complexity of palliative care service delivery.
	3. Improve access to education and certification opportunities for physicians, nurses, chaplains, and social workers.
Research and workforce organizations	4. Include prognosis, communication, and symptom management competencies for serious illnesses as a routine part of undergraduate, graduate medical and nursing training, and continuing medical and nursing education.
	1. Commit resources to the palliative care and hospice research priorities established by the NIH State of the Science conference and the three Institute of Medicine reports.
	2. Increase funding for palliative care and hospice research to 2% of total NIH-AHRQ budget (up from 0.5%).
Research and workforce organizations	3. Offer palliative care and hospice research fellowships and career development awards annually.

TABLE 1—Continued

Stakeholder Category	Actions
	<ol style="list-style-type: none"> <li data-bbox="460 300 965 499">4. Conduct research on clinical treatments and organizational approaches to delivering palliative care and hospice, including prospective studies of palliative care and hospice concurrent with disease-specific treatment across disease types and treatment settings.</li> <li data-bbox="460 505 965 586">5. Establish an NIH-AHRQ palliative care and hospice study section for quality peer reviews.</li> <li data-bbox="460 591 965 760">6. Establish cross-institute NIH strategy to increase research funding in palliative care and hospice, as called for by the U.S. Senate Appropriations Committee report for the Departments of Labor, Health and Human Services, and Education for FY 2011.</li> <li data-bbox="460 765 965 1025">7. Conduct a study of workforce trends, training capacity, and needs for hospice and palliative care workforce for the nation's medical centers, hospices, and outpatient and long-term care settings, as called for by the U.S. Senate Appropriations Committee report for the Departments of Labor, Health and Human Services, and Education for FY 2011.</li> </ol>

Note: Authors' distillation of policy options is discussed in the literature.

A 1997 Institute of Medicine (IOM) report entitled *Approaching Death: Improving Care at the End of Life* also called for policy changes aimed at strengthening the palliative care workforce. In part as a response to the IOM report, in 2006 hospice and palliative medicine was approved by the American Board of Medical Specialties as a subspecialty of ten parent specialties (including internal medicine, family medicine, surgery, pediatrics, and neurology) (American Board of Hospice and Palliative Medicine 2006). Subsequently, the Accreditation Council for Graduate Medical Education certified (AAHPM 2008) the first seventy-eight post-graduate fellowship training programs to develop the palliative medicine specialist workforce necessary to meet the nation's needs (Portenoy et al.

TABLE 2  
Policies to Improve Access to Quality Palliative and Hospice Care

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Improve Access to Palliative Care and Hospice Services
<p>1. Workforce</p> <p>Professional workforce capacity</p> <ul style="list-style-type: none"> <li>o Ensure postgraduate training (fellowship) opportunities for masters-prepared nurses and for physicians via exemption to (or increase in) the cap on graduate medical education (GME) slots for this area of workforce shortage.</li> <li>o Distribute currently unused GME slots to ACGME-accredited palliative medicine fellowship training programs.</li> </ul> <p>Educational and training capacity (Reynolds 2008)</p> <p>Support young medical and nursing faculty entering the field through HRSA Title VII-supported career development awards (similar to Title VII Geriatric Health Professions Training Programs).</p> <p>Encourage entry into the field through educational loan forgiveness for physicians and advance-practice nurses.</p> <p>2. Financial, licensing, and regulatory incentives for delivery of palliative care services for hospitals, nursing homes, and all providers receiving Medicare or Medicaid payments</p> <ul style="list-style-type: none"> <li>o Increase payments to hospitals and nursing homes providing quality palliative care and hospice services to patients in high-need categories; follow this after several years with financial penalties for failure to provide these services.</li> <li>o Require access to quality nonhospice and hospice palliative care services for eligible beneficiaries in all proposed models of payment reform (including bundled payments, accountable care organizations, and the patient-centered medical home).</li> <li>o Direct deemed regulatory bodies to develop either a voluntary certificate program or accreditation requirements for quality palliative care programs.</li> <li>o Require palliative care services meeting quality guidelines as a condition of accreditation and payment as a regulatory requirement for health care organizations receiving Medicare and Medicaid financing.</li> </ul>
Improve Quality of Palliative Care
<p>3. Health professional training and certification (Hager and Russell 2009; Weissman and Blust 2005)</p> <ul style="list-style-type: none"> <li>o Ensure adequate numbers of palliative care teaching faculty in the nation's nursing, social work, chaplaincy, and medical schools.</li> <li>o Mandate demonstration of core palliative care competencies at both undergraduate and postgraduate medical and nursing education levels as a condition of accreditation.</li> </ul> <p>4. Research to strengthen the evidence base (Field and Behrman 2003; Field and Cassel 1997; NIH 2004)</p>

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TABLE 2—Continued

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Improve Access to Palliative Care and Hospice Services
o Designate funding for the NIH, AHRQ, and VA to conduct research on prevention and relief of pain and other symptoms and to improve communication, decision support, and care transitions in advanced illness.
o Designate funding for career development awards in palliative and hospice care in all appropriate government research funding agencies.
o Direct government research funding agencies to develop research centers of excellence in palliative and hospice care.
o Direct comparative effectiveness research (CER) funding to evaluate palliative care and hospice delivery models, alternative approaches to pain and symptom management, and effective means of communication, decision support, and transitional care coordination for seriously ill patients and their families.
o Direct the secretary of health and human services to conduct demonstrations and pilot projects testing hospital-, nursing home-, and community-based palliative care and hospice programs for patients with multiple chronic conditions, functional decline, and/or serious illnesses.

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2006; Scharfenberger et al. 2008; Scott and Hughes 2006; von Gunten 2006).

A continuing barrier to physician specialty training in palliative medicine is the cap on Medicare-funded graduate medical education (GME) slots in U.S. teaching hospitals (AAMC 2009; Salsberg et al. 2008). Despite a 30 percent growth in the U.S. population and a doubling of the number of Americans over age sixty-five since 1997, the total number of Medicare-funded graduate medical education training slots has been capped at about 80,000 since the passage of the Balanced Budget Act in 1997 (AmMedNews 2009; Salsberg et al. 2008). At present, the distribution of GME slots is entirely within the purview of each teaching hospital and is not federally mandated. Since Medicare is the dominant funder of graduate medical education in the United States, a new subspecialty like palliative medicine has little power to secure GME-funded slots from long-standing and preexisting training programs. As a result, specialty training in palliative medicine is largely dependent on private-sector philanthropy. In recognition of the need for data to inform federal training priorities, the August 2010 U.S. Senate Appropriations Committee report for the Departments of Labor, Health and Human Services, and Education for FY 2011 included language

in its Health Professions Workforce Information and Analysis section calling for HRSA-sponsored studies on the adequacy of the palliative care workforce:

The (U.S. Senate Appropriations) Committee is aware that hospice and palliative medicine [HPM] improves quality, controls cost and enhances patient/family satisfaction for the rapidly expanding population of patients with serious or life-threatening illness. Therefore, the Committee encourages HRSA to study workforce trends, training capacity and need for HPM physicians, physician assistants and nurse practitioners in our Nation's academic medical centers, hospice organizations and palliative care programs.

### *Lack of Research on Palliative Care and Hospice*

Investment in research on palliative care and hospice is needed to ensure that care is based on reliable evidence and to test promising delivery models in a range of patient populations and settings. Even though the U.S. population is aging and persons with multiple chronic conditions and functional impairment account for the bulk of health care spending (Office of Assistant Secretary for Planning and Evaluation et al. 2010), a recent study found that less than 0.01 percent of total National Institutes of Health (NIH) extramural funding between 2003 and 2005 was for palliative care-related research (Gelfman and Morrison 2008). With rare exceptions (NPCRC 2010), not-for-profits and charitable foundations do not invest in research, thereby placing additional pressure on federal funding sources to fill the gaps. Reflecting awareness of this problem, the August 2010 U.S. Senate Appropriations Committee report for the Departments of Labor, Health and Human Services, and Education for FY 2011, in its section on the National Institutes of Health, called for a transinstitute strategy aimed at increasing funding for palliative care research:

Palliative Care.—The (Senate Appropriations) Committee strongly urges the NIH to develop a trans-Institute strategy for increasing funded research in palliative care for persons living with chronic and advanced illness. Research is needed on: treatment of pain and common non-pain symptoms across all chronic disease categories, which should include cancer, heart, renal and liver failure, lung disease, Alzheimer's disease and related dementias; methods to improve

communication about goals of care and treatment options between providers, patients, and caregivers; care models that maximize the likelihood that treatment delivered is consistent with patient wishes; and care models that improve coordination, transitions, caregiver support, and strengthen the likelihood of remaining at home.

In summary, the key barriers to ensuring access to quality palliative care for all Americans with advanced or serious illness include regulatory and accreditation requirements to redress variability in access to palliative care and hospice services based on geographic location, attending-physician biases, hospital size, and ownership (Dartmouth Institute for Health Policy and Clinical Practice 2008; Fisher, Bynum, and Skinner 2009; Goldsmith et al. 2008); primary and specialist-level physician, nursing, social work, and pharmacy palliative care education and training (Billings and Block 1997; Weissman and Blust 2005; Weissman et al. 2002); adequate compensation and loan forgiveness opportunities to attract professionals into the field; financial incentives encouraging workforce development and organizational commitment; investment in adequate research to develop an evidence base guiding and measuring quality of care (Gelfman and Morrison 2008); and public outreach and education on the value of palliative care and hospice. Opportunities to increase access to quality palliative care for all Americans are summarized in Tables 1 and 2.

### **Palliative Care and Hospice in the Affordable Care Act of 2010**

Although many provisions related to access to quality palliative care were ultimately removed from the original health reform bills, including the S.1150 Advance Care Planning and Compassionate Care Act (U.S. Senate 2009) and the Life Sustaining Treatment Preference Act (U.S. Congress 2009), several provisions directly relevant to hospice were enacted into law with the passage of the Affordable Care Act (ACA). These provisions focus exclusively on hospice (NHPCO 2010a) and include payment and quality reforms. They allow access to both hospice and curative/life-prolonging care at the same time for children and evaluate this model through demonstration projects for adults (ACA sections 3132, 3140, 2302, 3006, 3004).

Although not mandated in the ACA, the new law does enable the integration and participation of palliative care and hospice programs as a component of the new delivery and payment models, such as accountable care organizations (ACOs), patient-centered medical homes (PCMHs, also known as Health Homes), and the bundling of payments for a single episode of health care. Each of these models aims to improve quality and control cost for high-need patient populations by focusing on patient-centered, goal-driven, and intensive care coordination; the identification and treatment of problems before crises prompt preventable emergency department visits or hospitalizations; and shifting provider incentives from fee-for-service drivers of quantity to payment based on quality (see Table 3). Despite the potential for palliative care and hospice care to enhance the ability of new delivery and payment models to improve quality and reduce cost, there is as yet no mandate for their inclusion and no certainty about the likelihood of their integration in the future.

A major challenge to the success and scaling of these new delivery and payment models is the fact that the professional skills necessary to achieve their goals of coordinated and comprehensive care for high-risk high-need patient populations with serious and advanced illness, multimorbidity, and functional dependency are not widely available among health care providers in the United States. The lack of these skills is due to both the lack of training in care for the seriously and chronically ill and the long practice patterns of midcareer professionals derived from fee-for-service incentives driving acute- and specialist-level care. Efforts to improve competency in primary palliative care (pain and symptom management, communication about achievable goals for medical care, and management of serious and complex illness outside hospitals) for the nation's medical and nursing workforce will require changes in undergraduate and graduate training curricula, as well as improved access to midcareer training (AAHPM 2011; PCEP 2011).

The skills needed to deliver such training and to provide specialty-level palliative care are, however, available in the staff of the nation's 1,500 palliative care and 3,400 hospice programs. The rapid growth of palliative care programs in the last decade is a hospital and health professional response to the unmet needs of a seriously and chronically ill patient population with significant care requirements, who are not predictably dying and are therefore ineligible for hospice care. As a consequence, the majority of mid- to large-size hospitals in the U.S. already have palliative care teams with relevant skills (CAPC 2010). Similarly,



TABLE 3  
 Opportunities to Strengthen Access to Quality Palliative Care and Hospice in  
 the Affordable Care Act of 2010

Palliative Care and Hospice Opportunities	Provisions of Affordable Care Act
Hospice-specific provisions	<ol style="list-style-type: none"> <li>1. Section 3132: Market basket cuts and productivity adjustments for hospice.</li> <li>2. Section 3132: Hospice payment reform; requires data collection, face-to-face recertification of hospice patients by an MD or nurse practitioner before 180-day limit.</li> <li>3. Section 3140: Medicare concurrent care demonstration; allows study of simultaneous hospice and life-prolonging treatments under Medicare; 15 sites.</li> <li>4. Section 3202: Concurrent (curative and palliative) care for children in Medicaid and CHIP; October 2013.</li> <li>5. Section 3006: Tests of value-based purchasing (VBP) for hospice; implementation October 2016.</li> <li>6. Section 3004: Quality-reporting mandate to be preceded by hospice and palliative care measure endorsement before October 2012 for implementation October 2013.</li> </ol>
Value-based purchasing and pay for performance	<ol style="list-style-type: none"> <li>7. Section 3001: Establishes VBP for hospital payments based on performance on quality measures.</li> <li>8. Section 3008: Provides for payment penalties for hospital-acquired conditions.</li> <li>9. Section 3025: Provides for payment penalties for risk-adjusted readmission rate.</li> <li>10. Section 3005: Establishes VBP for prospective-payment-exempt cancer hospitals.</li> <li>11. Section 3006: Provides for transition to VBP for home health agencies, skilled nursing facilities (SNFs), and ambulatory surgery.</li> </ol>
Delivery system reforms and coordinated care	<ol style="list-style-type: none"> <li>12. Section 3022: Medicare shared savings and accountable care organizations; promotes accountability for overall care of patients and encourages care processes and coordination focused on quality and efficiency.</li> </ol>

*Continued*

TABLE 3—*Continued*

Palliative Care and Hospice Opportunities	Provisions of Affordable Care Act
	<p>13. Section 3023: Payment-bundling pilot; tests impact on quality and cost of a single “bundled” payment for all aspects of an episode of care. Encourages coordinated community care services and aligns incentives to reduce use of the most expensive setting for care.</p> <p>14. Section 3024: Independence-at-home demonstration tests bringing care to the home for the homebound; aligns incentives to coordinate and deliver all care needed, and rewards coordination, quality, and maintaining beneficiaries in their homes.</p> <p>15. Section 3026: Community-based care transitions; supports payment for care coordination and safe transitions to the community.</p> <p>16. Section 3502: Community health teams to support patient-centered medical home.</p>
Innovation/cost control	<p>17. Section 3021: CMS’s Center for Medicare and Medicaid Innovation; provides capacity to test delivery and payment models designed to strengthen quality and control cost. Successful pilots can be expanded nationwide.</p> <p>18. Section 3403: Independent Medicare advisory board; establishes 15-member group charged with developing legislative proposals to reduce excess Medicare spending and improve quality.</p>
Workforce	<p>19. Section 5101: National Health Care Workforce Commission; establishes authority to evaluate adequacy of health workforce to coordinate federal, state, and local workforce initiatives, and prioritize workforce investments based on population needs.</p> <p>20. Sections 5201, 5202, 5203: Provide for loan repayment and student loan supports.</p>

TABLE 3—*Continued*

Palliative Care and Hospice Opportunities	Provisions of Affordable Care Act
Quality	21. Section 6301: Patient-centered outcomes research. 22. Section 3011: National health care quality strategy. 23. Section 3014: Quality measurement.

*Note:* Legislative provisions are relevant to palliative care and hospice services.

the growth in numbers and utilization of hospice over the last decade has resulted in a national workforce trained and experienced in caring for the targeted high-need patient population. Linking palliative care and hospice teams to implementing new delivery models may increase the likelihood of their achieving their quality and health care value objectives (Rodgers 2010). The metrics for quality palliative care and hospice necessary to include them in the specifications for the new delivery and payment models aimed at improving care value for this patient population will be available by October 2012, as required in the Affordable Care Act (sec. 3004).

## Conclusions

The evolution and growth of palliative care and hospice in the United States have resulted from the combined investments of both the public and the private sectors. The twenty-five-year-old Medicare hospice benefit exemplifies the role and impact of palliative care at the end of life and the new delivery and payment models encouraged by the Affordable Care Act and aimed at a high-risk high-need target population have the potential to strengthen palliative care capacity in the acute, postacute, and long-term care settings for seriously ill patients who are not dying. Substantial private-sector contributions exceeding \$300 million in the last twenty-five years (Meier, Isaacs, and Hughes 2010) have created the new field of palliative care outside hospice and are reflected in the growth of hospital palliative care services, education and training for health professionals, and formal recognition of subspecialty status for physicians and nurses. Major health care organizations such as the American Medical Association's nationally disseminated physician

education initiative Education for Physicians in End-of-Life Care and the American Hospital Association's annual Circle of Life awards for quality palliative care programs have also made sustained and influential commitments to advancing access to quality palliative care for the seriously ill. Free from the constraints limiting government-funded health insurance, commercial and integrated health plans have experimented with creative payment models resulting in better value by, for example, allowing access to simultaneous hospice and curative therapies as well as coverage of complex care coordination and home-based palliative care services (Brumley et al. 2007; Krakauer, Spettel and Wade 2009; Spettel et al. 2009). The combined and sustained commitment of both the private and the public sectors will be necessary to bring the palliative care innovation to scale in the United States.

### *Scaling Palliative Care by Ensuring Access for All Americans in Need*

Palliative care and hospice care teams advance the National Priorities Partners' priorities for America's highest-risk and highest-need patient populations, addressing symptom distress and quality of life, care coordination, patient and family support and engagement, safety (through prevention of wrong care such as risky and unnecessary tests and procedures), and associated reductions in overuse (NQF 2009). Ensuring access to high-quality palliative care for all Americans who might benefit requires that providers be trained to deliver this kind of care; that an evidence base exists to ensure quality; that health care organizations have the capacity to provide palliative care; and that the public understand what palliative care and hospice are and demand such care from their clinicians. We have come a long way toward achieving these goals, and ensuring that palliative care is reliably available to America's sickest and most vulnerable patients and their families is now at a tipping point.

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