AMERICA’S CARE OF SERIOUS ILLNESS

A State-by-State Report Card on Access to Palliative Care in Our Nation’s Hospitals
Preface

This report, an update of the 2008 publication *America’s Care of Serious Illness: A State-by-State Report Card on Access to Palliative Care in Our Nation’s Hospitals*, is the result of collaboration between the Center to Advance Palliative Care (CAPC) and the National Palliative Care Research Center (NPCRC). Highlighting the current prevalence of hospital palliative care programs, the report was undertaken in an effort to understand changes in access to such programs in the United States.

Drawing on the clinical and operational expertise of leaders in the field of palliative care, the research team was led by R. Sean Morrison, MD, Director of the National Palliative Care Research Center, and Diane E. Meier, MD, Director of the Center to Advance Palliative Care. Rachel Augustin, MPH, research officer for the Center to Advance Palliative Care, also contributed to the analyses contained in this report.

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The major findings contained in this report build on research first described in “Variability in access to hospital palliative care in the United States” (Journal of Palliative Medicine, October 2008). The data were obtained primarily from the American Hospital Association (AHA) Annual Survey Database™ for fiscal year 2009. Additional data for the 2011 report were obtained from the American Board of Medical Specialties (ABMS), American Academy of Hospice and Palliative Medicine (AAHPM), National Board for Certification of Hospice and Palliative Nurses and the Dartmouth Atlas.

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INTRODUCTION

Palliative Care: The New Paradigm for Managing Serious Illness

Today, approximately ninety million Americans are living with serious illness, and this number is expected to more than double over the next twenty-five years.¹

We are also an aging nation. By the year 2030, according to the Administration on Aging (AoA), there will be more than 72.1 million Americans over age sixty-five in the U.S. (20 percent of the total U.S. population), and more than twice the number in 2000.²

While baby boomers will experience unprecedented longevity (those who reach sixty-five can expect to live well into their mid-eighties), these additional years carry a significant burden of chronic illness. Most will live with multiple, long-term medical conditions and need expert, compassionate and coordinated delivery of health care.

Yet despite the highest per-capita spending on health care in the world, more than 50 percent of caregivers of Americans hospitalized with a serious illness report less than optimal care,³ and more than 30 percent of families lose most or all of their savings while caring for a loved one with a serious illness.⁴

Of the 1.5 million Americans who die of a chronic illness each year, more than 70 percent are admitted to a hospital during the last six months of life.⁵ Recent studies also show that most people living with a serious illness experience inadequately treated symptoms, fragmented care, poor communication with

⁵ Dartmouth Atlas of Health Care.
their doctors and enormous strains on their family caregivers. Consider the following:

- 1 in 4 patients report inadequate treatment of pain and shortness of breath.\(^6\)
- 1 in 3 families report inadequate emotional support.\(^7\)
- 1 in 3 patients report that they receive no education on how to treat their pain and other symptoms following a hospital stay.\(^8\)
- 1 in 3 patients are not provided with arrangements for follow-up care after hospital discharge.\(^9\)

To address these gaps in care, hospitals have been quietly establishing, over the last decade, what has become a growing trend—palliative care programs. Palliative care is specialized medical care focused on providing relief from the symptoms, pain and stresses of a serious illness—whatever the diagnosis. It is appropriate at any age and at any stage of a serious illness, and can be provided together with curative treatment. The goal is to improve quality of life for both the patient and the family.

Palliative care is team-based care that includes specialized physicians, nurses, social workers and others (such as chaplains) who work with a patient’s other doctors to provide an extra layer of support. These specialists treat pain and other symptoms; provide time-intensive communication; support complex medical decision making; ensure practical, spiritual and psychological support; and coordinate care across all the settings where patients receive medical care. An important focus is the plan of care, which is developed after in-depth consultation to ensure that medical treatments align with the needs, goals and priorities of the patient and the family.

Palliative care is not defined by a person’s life expectancy. Indeed, patients receiving palliative care from the point of diagnosis, or may live for years with one or more chronic diseases.
The good news is that in the last ten years the number of palliative care teams in hospitals has more than doubled in response to the increasing numbers and needs of Americans living with serious and chronic illnesses, and the caregiving realities faced by their families.

The bad news is that despite the myriad benefits of palliative care, as well as its recent growth, more progress is needed. Millions of Americans with serious illness do not yet have access to palliative care from the point of diagnosis throughout the course of illness. Availability varies considerably by region and by state.

This Report Card examines variation in access to palliative care at the state level in order to help both the public and policymakers increase the availability of these services for all Americans in need.

The 2011 Report Card website can be found at www.capc.org/reportcard.
Over the last ten years palliative care has been one of the fastest-growing trends in health care. In fact, the number of palliative care programs within hospital settings has increased by 138 percent since 2000. Surprisingly, this development has occurred with little notice and within the current health care system. The reason for this quiet but steady growth is that palliative care has been embraced by patients and their families for the simple reason that it gives them control and choice over their own care and responds to their needs as they themselves have defined them. The strong partnership of patient, family and the palliative care team ensures that treatment goals are aligned and coordinated, and that open and full communication is maintained throughout the long, complex course of a serious illness.

Recent public opinion research by the national polling firm Public Opinion Strategies has shown that once informed about palliative care, 92 percent of the American public are highly likely to consider palliative care for themselves or their families if they have a serious illness. Ninety-two percent also said it is important that palliative care services be made available at all hospitals for patients with serious illness and their families throughout the United States. The data also show a positive response to palliative care regardless of party affiliation.

To meet the growing demand for and access to palliative care, specific changes in our health care system are needed now.
While this Report Card demonstrates considerable growth in the number of palliative care programs across the United States, barriers in three key areas—workforce, research and access—currently prevent full availability of palliative care for all patients and families facing serious or life-threatening illness. Specifically, three key policy initiatives are needed:

- **Investment in a trained workforce to ensure sufficient numbers of specialists both to teach all clinicians the fundamentals and to directly provide high-quality palliative care for the highest-risk and most complex patients;**

- **Investment in the research necessary to establish a strong science base for palliative care and to expand palliative care’s ability to improve both quality and length of life;**

- **Investment in health care system capacity by requiring delivery of high-quality palliative care in hospitals, nursing homes and community settings through changes in measurement, payment and accreditation standards.**

## Workforce

A major barrier facing the expansion of palliative care services is the lack of palliative medicine physicians. Where there is approximately one cardiologist for every 71 persons experiencing a heart attack and one oncologist for every 141 newly diagnosed cancer patients, there is only one palliative medicine physician for every 1,200 persons living with a serious or life-threatening illness.

There are two principal reasons for the shortage of palliative medicine providers. First, palliative medicine is a new specialty, formally recognized in 2007. Thus, although the number of training programs is increasing, as of 2010 there were only 73 accredited allopathic subspecialty training fellowship programs in the United States, collectively producing approximately 86 new palliative medicine physicians per year. Second, Medicare funding, which currently supports the majority of post–medical school residency training for physician specialties in the United States, does not support palliative medicine specialty training. This is a consequence of the 1997 Balanced Budget Act’s cap on Medicare-funded graduate medical education (GME) slots. The majority of academic medical centers—the site of training for medical students, residents and fellows—currently are at or exceed their GME residency cap. As a result, Medicare dollars are unavailable for training...
palliative medicine physicians, and current palliative medicine fellowship training programs are inadequately supported by scarce philanthropic dollars.

Three initiatives are necessary to ensure that Americans with serious illness and their families have access to quality palliative care. First, future generations of palliative medicine specialists require support and expansion of palliative medicine fellowship training programs. Demand for this training is high, as palliative medicine is the fastest-growing medical subspecialty in the United States and expansion and support of fellowship programs is needed. Second, a substantial number of midcareer physicians are seeking training in order to transition from their current field of practice into palliative medicine. Third, all physicians who care for patients with serious illness should be trained in the core principles of palliative medicine to ensure that they know how to communicate with seriously ill patients and treat pain and other distressing symptoms.

Several policy initiatives are likely to have a major impact on increasing the current number of palliative care clinicians, including proposals to:

- **Lift the GME cap on Medicare-funded residency positions and redistribute unused GME slots to support Accreditation Council for Graduate Medical Education (ACGME)–approved palliative medicine fellowship training.**

- **Establish loan-forgiveness programs for palliative care physicians and nurses through the Health Resources and Services Administration (HRSA) to promote palliative care as a viable career path for young health care professionals.**

- **Create HRSA Title VII–supported career development awards (similar to Geriatric Health Professions Training Programs) to support clinician-educators who can integrate palliative care into medical, nursing school and postgraduate training curricula.**

- **Establish HRSA awards to support retraining of midcareer current medical and nursing workforce for this new specialty.**

- **Require CME training for referring physicians as a condition of licensure at the state level—similar to California’s provision for pain management training—that would ensure physician competency in the core principles and practice of palliative medicine.**
Research

Increased funding for palliative care research is needed to strengthen clinical practice and improve health care delivery that will maximize quality of life for patients and families facing serious and chronic illnesses.

The National Institutes of Health (NIH) and the Institute of Medicine have repeatedly called for substantial investments in palliative care research. Yet, as of 2009, there were only 114 active awarded NIH grants supporting palliative care research. While the growth of the palliative care field has been remarkable, there is a need to strengthen the knowledge base that supports basic elements of clinical practice in pain and symptom management, communication skills and care coordination. To that end, specific focus areas and funding mechanisms for palliative care research should be developed in all NIH institutes, the Agency for Healthcare Research and Quality (AHRQ) as well as the Veterans Administration.

Policy initiatives to address this knowledge gap are straightforward and easily integrated within current biomedical research funding structures:

> NIH/AHRQ should allocate 2 percent (increase from 0.01 percent between 2003–2005) of their current budgets to focus on symptom relief, communication in the setting of serious illness and research focused on the impact of concurrent palliative care along with disease-directed therapies for patients with serious illness.

> NIH should establish an Office of Palliative Care Research modeled after the Office of AIDS Research to oversee and ensure appropriate distribution of research funding.

> Existing NIH career development award mechanisms should be utilized to support junior investigators and midcareer palliative care investigators in order to build a critical mass of established palliative care researchers.

Access and Quality

While physician and (in some states) advanced practice nursing services provided by a palliative care team are covered by most private insurance, as well as Medicare and Medicaid, palliative care is not readily accessible to all Americans. It is offered...
primarily in hospital settings, with only a few major medical centers providing outpatient or home-delivered palliative care programs. As of 2009, 63 percent of U.S. hospitals with at least fifty beds and 85 percent of hospitals with more than 300 beds reported the presence of a palliative care team. While this represents an increase of 138 percent from 2000, it is not good enough. Currently, there are only about 1,568 hospitals out of a total of 2,489 (American Hospital Association estimate for 2010) nationwide that offer some type of palliative care program.

Part of the problem is that the current business model for palliative care is based on cost avoidance (reducing unwanted and unnecessary utilization) rather than on revenue generation. This model is unusual in health care, requires sophisticated analytic methods to employ successfully and is thus difficult to integrate into hospitals’ current operating metrics. Additionally, accreditation standards for hospitals and nursing homes do not currently require the presence of a quality palliative care program despite publication of consensus standards by the National Quality Forum (NQF). Near-term policy solutions that could increase access to quality palliative care are as follows:

> The reimbursement structure for palliative care should enable hospitals and nursing homes to support provision of palliative care services. Palliative care specialists, like critical care physicians, should be compensated at a level commensurate with the complexity and seriousness of illness in the patients they are serving. That includes the work of the entire interdisciplinary team (doctor, nurse, social worker and others). Advanced practice nurses delivering palliative care are allowed to bill fee for service in some states, but not all. To improve access to palliative care services throughout the country, advanced practice nurse compensation should be standardized.

> Given the high costs and poor quality of care received by patients with serious illnesses, new delivery and payment models rewarding whole-person care instead of fragmented fee-for-service care should ensure access to palliative care as a core component of available services.

> Palliative care teams meeting quality standards should be a condition of accreditation for all U.S. hospitals and nursing homes.

Approximately 63 percent of hospitals report a palliative care program.
Palliative care teams are tackling a perfect storm. Unprecedented growth of an aging population; the failure to recognize and treat pain and other distressing symptoms experienced by seriously ill people; the widespread availability and use of costly medical technologies that fail to restore health and functional independence, or a quality of life acceptable to the patient; exponential cost increases; and dissatisfaction with and confusion about the medical care system for those with serious illness—all form the context for the rapid growth of the field of palliative care.

Expert attention to physical and psychological symptoms and improved communication and coordination—the domains of palliative care—form the foundation for effective health care. Yet, this is not what seriously ill patients usually get.

Typically, doctors generate a list of medical problems—based upon discrete organ systems and diseases—and approach the “problem list” as a series of items on a checklist. Although effective for single disease states, this approach falls apart in the setting of multiple diseases and serious conditions interacting and influencing one another. Emotional and spiritual distress and enormous caregiver needs make the situation even more complex. In New York City, for example, the average person with a serious illness is receiving care from twelve different specialist physicians, with no single individual coordinating care.12

In contrast, palliative care teams begin by interviewing patients about their goals for care, the symptoms and other issues that bother them and the needs of their families. By starting with the patient's and family's priorities and goals, palliative care teams ensure that the care received is aligned with patient and family needs and is driven by their agenda, not that of the health care system or the physician. Furthermore, and perhaps most importantly, palliative care ensures that the person is viewed in his or her entirety, not as a collection of organs and medical problems.

By following this approach:

**Palliative care teams reduce high levels of suffering and distress among patients with serious illness, at any age and at any stage of disease.** People with serious and life-threatening illnesses live not only with multiple diseases (e.g., advanced heart and lung disease, diabetes, arthritis, cancer), but also with multiple symptoms (e.g., pain, anxiety, shortness of breath, fatigue, depression, sleep disorders). Palliative care reduces pain and other debilitating symptoms, and it can be provided at any age and any stage in the course of an illness, along with curative treatment.

**Palliative care teams improve communication among patients, families and health care providers.** Palliative care results in the identification of achievable care goals, better patient and family understanding of disease and treatment choices, and improved communication among patients, families and all health care providers.

**Palliative care teams address the needs of family caregivers as they cope with and care for a loved one with serious illness.** By identifying family needs, fears and knowledge gaps, palliative care programs have been shown to improve a family's feeling of confidence and security in the setting of a loved one’s serious illness. People with serious illnesses live with enormous caregiving requirements (e.g., assistance with feeding, bathing, toileting, walking); complicated transitions (e.g., rehabilitation, visiting-nurse services, nursing homes, care coordination) and many other complex needs. Caregivers need practical and emotional support, and palliative care ensures both.
Palliative care teams reduce unwanted, unnecessary and painful interventions. By establishing patients’ goals and focusing on what are important and achievable outcomes for medical treatment, palliative care teams ensure that patients receive the most effective and timely treatments and that their valuable time and energy is protected from burdensome tests and procedures that will not lead to improvements or changes in care.

Palliative care can improve survival. A recent study published in the *New England Journal of Medicine* showed that receiving palliative care early in the treatment of advanced lung cancer led to significant improvements in both quality of life and mood. As compared with patients receiving only disease-directed care, patients receiving early palliative care required less emergency hospital and ICU care, and survived approximately 2.7 months longer.13

Palliative care teams improve patient and family satisfaction. Surveys of patients cared for by palliative care teams routinely reveal high patient and family satisfaction—among the highest rates observed in any study of hospitalized and seriously ill patients. A recent poll conducted by Public Opinion Strategies also shows that palliative care provides what people want: quality of life; relief from suffering; support for family caregivers; control and choice.


Palliative care improves quality of care while reducing costs. About 10 percent of all Medicare beneficiaries have five or more chronic conditions and two-thirds of Medicare spending goes to cover their care. This patient population is also the most likely to benefit from palliative care. Recent studies indicate, in fact, that by focusing on the needs of our most complex patients by matching treatments with their goals, improving their quality of life and providing support for care at home—thus helping to avoid preventable emergency hospitalizations—palliative care teams can contribute to substantial cost savings.15 Savings are the result of patients’ decisions to shift their care out of the hospital and into the community, usually into their own home, ultimately reducing costs.


As mentioned earlier in this report, once informed about palliative care, 92 percent of the American public wants access to palliative care programs in hospitals nationwide.\textsuperscript{16} If this demand is met, quality of care for those patients with serious and chronic illnesses will go up but costs of care will go down. In fact, according to a recent report published by the Institute of Medicine, if palliative care teams were fully integrated into the nation’s hospitals, total savings could exceed $6 billion per year.\textsuperscript{17}

In summary, coordinated care by an interdisciplinary team is at the heart of palliative care and represents the best response to the long-term nature of chronic, multifaceted illnesses. Studies demonstrate that when patients have control of their care by working with palliative care teams to set treatment goals, quality of care is improved as well as patient and family satisfaction. Such an approach reduces the need for hospitalization and duplicative or unnecessary testing and medication and ultimately reduces costs for patients, families and health care providers alike.

\textsuperscript{16} Public Opinion Strategies Poll, April 2011.

The 2011 State-by-State Report Card Shows Improvement

The 2011 State-by-State Report Card updates our 2008 Report Card.\(^\text{18}\) Reflecting data from the American Hospital Association Annual Survey Database\(^\text{19}\) for fiscal year 2009, we again examine prevalence and geographic variations in access to palliative care in U.S. hospitals. Specifically, in 2011 we examine:

1. Patient access to palliative care services in hospitals; and

2. Patient access to board-certified palliative care professionals (e.g., physicians and nurses).

Hospitals containing fifty or more beds are the primary focus of the 2011 Report Card. Hospitals with fewer than fifty beds see only a small number of patients with serious or life-threatening illnesses, and are therefore unlikely to be able to support the model of an interdisciplinary palliative care consultation team that includes, at minimum, a specialty-level palliative care physician, nurse and social worker. Also excluded from the study are rehabilitation hospitals; psychiatric hospitals; subacute and chronic-care facilities; eye, ear, nose and throat hospitals; pediatric hospitals; hospitals under federal control (e.g., V.A. and military hospitals); hospitals located outside the fifty states and the District of Columbia; and hospitals that did not respond to the AHA Annual Survey Database\(^\text{TM}\).


\(^{19}\) American Hospital Association Annual Survey\(^\text{TM}\) for fiscal year 2009.
Findings in 2011 demonstrate considerable improvement since the 2008 Report Card. However, significant variation still persists from state to state. The 2011 analysis also demonstrates fluctuations in the number of hospital palliative care teams within a given state from year to year.

Table 1 of the Appendix presents the state-by-state findings of hospitals evaluated in this study—hospitals with fifty or more beds. Table 1 also shows the prevalence of palliative care teams among sole community provider hospitals, larger hospitals with 300 or more beds and small hospitals with fewer than fifty beds.

What Are the Key Predictors of Access to Palliative Care?

As we have seen in other areas of our health care system, we found wide geographic variation in access to palliative care services. Factors predicting the presence of a hospital palliative care team have not changed markedly since the 2008 Report Card.

- **Large hospitals with 300 or more beds are more likely to report a palliative care team (85 percent).**

- **Public hospitals (54 percent), for-profit hospitals (26 percent), and sole community provider hospitals (37 percent) are less likely to report a palliative care team.**

- **On average, midsize (50–300 beds) and large hospitals (over 300 beds) are more likely to be not-for-profit.**

Improvements Since the 2008 Report Card

Since our last report, the overall prevalence of hospital palliative care teams among hospitals with fifty or more beds increased 13.3 percent in the Midwest, 21.7 percent in the Northeast, 23.7 percent in the South and 29.3 percent in the West. The cumulative national average is 63 percent (1,568 out of 2,489 study hospitals).
There have also been improvements at the state level. In 2008, the eleven states with the lowest prevalence rates were: Mississippi (10 percent), Alabama (16 percent), and Oklahoma (19 percent), Nevada (23 percent), Wyoming (25 percent), Louisiana (27 percent), South Carolina (30 percent), Texas (33 percent), New Mexico (33 percent), Kentucky (37 percent) and Georgia (38 percent).

Today, only Delaware and Mississippi get an F (20 percent). However, Mississippi demonstrated substantial improvement since 2008, doubling its prevalence from 10 to 20 percent. Alabama increased from 16 to 28 percent, and Oklahoma increased from 19 to 30 percent. Seven states improved their grades from a D to a C: Georgia, Kentucky, New Mexico, Texas, South Carolina, Louisiana and Wyoming. Nevada saw dramatic gains, rising from a D to a B grade.

States getting an A nearly tripled from three in the 2008 Report Card to seven plus the District of Columbia in the 2011 Report Card. Along with the District of Columbia (100 percent), states receiving an A grade now include: Vermont (100 percent), Nebraska (93 percent), Maryland (90 percent), Minnesota (89 percent), Oregon (88 percent), Rhode Island (88 percent) and Washington (83 percent).

Fifty percent of states received a B grade. The top nine states with B grades, ranging from 75 to 80 percent, include: New Jersey (80 percent), Ohio (80 percent), Virginia (78 percent), South Dakota (78 percent), New Hampshire (77 percent), Michigan (76 percent), and Missouri, New York and North Carolina (each with 75 percent).
### Does Your State Make the Grade?

Despite the rapid growth of palliative care teams in our nation’s hospitals and improvement since the last Report Card, access to palliative care services in the United States must improve if we are to adequately care for our sickest patients. In 2008, our nation received an overall grade of C. In 2011, the country receives an overall grade of B. Seven states plus the District of Columbia now receive a grade of A, with more than 80 percent of hospitals reporting palliative care services. More than half of the fifty states receive a grade of B. Fewer than 25 percent of states now need significant improvement (C). Approximately 12 percent receive nonpassing grades of D or F.

#### Top performers (programs in 83% to 100% of hospitals):

**States receiving an A grade**

- District of Columbia 100%
- Maryland 90%
- Minnesota 89%
- Nebraska 93%
- Oregon 88%
- Rhode Island 88%
- Vermont 100%
- Washington 83%

#### On their way (programs in 61% to 80% of hospitals):

**States receiving a B grade**

- Arizona 69%
- California 67%
- Colorado 73%
- Connecticut 72%
- Florida 62%
- Idaho 63%
- Illinois 67%
- Indiana 63%
- Iowa 61%
- Maine 71%
- Massachusetts 67%
- Michigan 76%
- Missouri 75%
- Montana 67%
- Nevada 69%
- New Hampshire 77%
- New Jersey 80%
- New York 75%
- North Carolina 75%
- North Dakota 67%

**States in the middle (programs in 42% to 60% of hospitals):**

**States receiving a C grade**

- Georgia 43%
- Hawaii 58%
- Kansas 47%
- Kentucky 55%
- Louisiana 43%
- New Mexico 44%
- South Carolina 51%
- Tennessee 52%
- Texas 42%
- Utah 60%
- West Virginia 55%
- Wyoming 50%

#### States that need significant improvement (programs in 28% to 38% of hospitals):

**States receiving a D grade**

- Alabama 28%
- Alaska 29%
- Arkansas 38%
- Oklahoma 30%

#### States with little or no access (programs in 0% to 20% of hospitals):

**States receiving an F grade**

- Delaware 20%
- Mississippi 20%
Where You Live Matters

“Geography is destiny,” as the Dartmouth Atlas researchers have often pointed out, appears to hold true when speaking of access to hospitals offering palliative care. In the Northeast, 73 percent of hospitals with fifty or more beds report a palliative care team, compared to only 51 percent in the South. Among hospitals with fewer than fifty beds, your chances of having access to a palliative care team are extremely limited, particularly in the South, where only 14 percent of small hospitals (fewer than fifty beds) report having palliative care services.

Nationally, the prevalence of palliative care in large hospitals with 300 or more beds is 85 percent, ranging from 50 percent (Alabama and Delaware) to 100 percent in nineteen states. The lowest prevalence rates of palliative care in large hospitals were found in Alabama (50 percent) and Delaware (50 percent). The highest rates in large hospitals were found in nineteen states with 100 percent prevalence (see Appendix Table 1).

The number of small hospitals (under fifty beds) varies widely by state. For example, four states (Connecticut, Delaware, New Jersey and Rhode Island) and the District of Columbia do not report any hospitals of this size. The 2011 Report Card shows that the national prevalence rate for palliative care services in small hospitals is 22 percent. The lowest prevalence rates in small hospitals are found in Louisiana (0 percent), Mississippi (0 percent) and Alabama (4 percent). The highest prevalence rates for small hospitals are found in New Hampshire (62 percent) and Maine (58 percent).

Underserved Populations Have Less Access to Palliative Care

In addition to marked disparities in geographic availability, we observed low rates of access to palliative care in public and sole community provider hospitals. Public and sole community provider hospitals often serve as the only option for medical care for the forty-seven million Americans lacking health care coverage or living in geographically isolated communities. Therefore, our finding that the majority of these institutions continue to lack palliative care services speaks to a disparity in access to comprehensive care for America’s most vulnerable patient populations. Notably:

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Only 54 percent of public hospitals provide their patients access to palliative care.

Fewer than 40 percent of sole community provider hospitals offer their patients access to palliative care.

Lack of Board-Certified Palliative Medicine Physicians

Improving access to palliative care for America’s patients and families requires a workforce highly trained in the fundamentals of palliative medicine. Today in the United States there are 2,887 physicians board-certified in palliative medicine.

Prevalence of board-certified palliative care physicians varies across states. The highest rates are to be found in Hawaii (1 per 154 Medicare deaths), New Mexico (1 per 222 Medicare deaths) and Colorado (1 per 244 Medicare deaths). The lowest rates are in Mississippi (1 per 1,698 Medicare deaths), Rhode Island (1 per 1,267 Medicare deaths), Montana (1 per 1,218 Medicare deaths), Delaware (1 per 1,060 Medicare deaths) and South Dakota (1 per 1,037 Medicare deaths).

Table 2 of the Appendix presents a state-by-state comparison of the number of board-certified physicians as well as advanced practice nurses and registered nurses.

Hawaii, New Mexico and Colorado have the greatest number of board-certified palliative care physicians.
Despite rapid improvements over the last few years, people living with a serious illness still experience significant disparities in access to a hospital that provides palliative care. Some areas of the United States are better equipped than others, and some hospitals are more committed than others to providing these services.

The ultimate goal of palliative care is to improve overall quality of life and quality of care for patients experiencing serious and chronic illnesses and their families. To benefit from palliative care, however, patients and their caregivers must be able to access these services in their local hospital. Physicians in training must learn from direct experience at the bedside with high-quality hospital palliative care teams.

Focused efforts by hospital administrators, the health care community and policymakers are required to promote the development of quality palliative care programs in all hospitals, with special attention needed in small, rural, public and for-profit hospitals (see “Policy Imperatives”). This will result in a more efficient and effective use of hospital resources, and will enhance the quality of care delivered to our nation’s most seriously ill patients and their families.
Studies over the past twenty years have conclusively demonstrated that too many seriously ill Americans experience treatable pain and distress and are financially devastated because of the high costs of medical care. At the same time, rising costs threaten Medicare just as millions of boomers are turning to it for health insurance coverage. Palliative care offers a logical and patient-centered approach to improving medical care by focusing on quality of life and ensuring that care is matched to patient and family goals.

Patients who have the information they need to choose care plans that meet their personal goals mean a substantial reduction in harmful and unnecessary hospitalizations for the highest-risk, most vulnerable patient population. Policy initiatives that address workforce, research and patient access could rapidly bring palliative care to scale in the United States. The implementation of such policies would help meet the needs of our sickest children and a growing population of older Americans with long-term chronic conditions.
Although this report assigned grades to states, regions and the nation based on the percentage of hospitals (with fifty or more beds) that reported a palliative care team to the American Hospital Association, it may be useful in the future to look more closely at how hospitals of various sizes and types rate.

Table 1, “Prevalence and Distribution of Palliative Care in U.S. Hospitals,” lists percentages and raw numbers of hospitals reporting palliative care programs by hospital size (50-plus, 300-plus, and fewer than 50 beds) and type within each state and region and for the nation overall. Note: The number of public and for-profit hospitals is a subset of 50-plus hospital beds.

Table 2, “Prevalence of Palliative Care Health Care Professionals,” lists numbers of physicians, advanced practice nurses and registered nurses who are certified in palliative care. It also shows the numbers of Medicare deaths (overall and in the hospital) per certified palliative care clinician to indicate how the distribution of qualified professionals affects quality of care for our sickest hospitalized patients. These numbers are also listed by state, region and the entire country for comparison.

Please refer to the 2011 Report Card website (www.capc.org/reportcard) for the methodology used in this report.

The Glossary contains terms used throughout this report, along with others that are common in similar publications.

21 Physicians are certified in hospice and palliative medicine in each state by either the American Board of Medical Specialties (ABMS) or the American Board of Hospice and Palliative Medicine (ABHPM). The information includes results from the 2008 ABMS certification examination. As of the writing of this report, the 2010 exam results were unavailable. Statistics are derived from the Official ABMS Directory of Board Certified Medical Specialists provided by Elsevier, and the ABHPM directory database of board-certified diplomates provided by the American Academy of Hospice and Palliative Medicine (AAHPM).
Table 1  Prevalence and Distribution of Palliative Care in U.S. Hospitals

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<th>PERCENT OF HOSPITALS REPORTING A PALLIATIVE CARE PROGRAM</th>
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Table 1  Prevalence and Distribution of Palliative Care in U.S. Hospitals (continued)

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<th>Sole Community Provider</th>
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<td>46% (6/13)</td>
<td>8% (1/12)</td>
<td>79% (15/19)</td>
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<td>55% (29/53)</td>
<td>0% (0/7)</td>
<td>80% (4/5)</td>
<td>33% (2/6)</td>
<td>92% (12/13)</td>
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<tr>
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<td>C</td>
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<td>36% (4/11)</td>
<td>32% (8/25)</td>
<td>0% (0/3)</td>
<td>67% (8/12)</td>
</tr>
<tr>
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<td>90% (37/41)</td>
<td>100% (1/1)</td>
<td>- (0/0)</td>
<td>- (0/0)</td>
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<td>25% (4/16)</td>
<td>8% (1/13)</td>
<td>70% (7/10)</td>
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<tr>
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<td>B</td>
<td>75% (55/73)</td>
<td>75% (3/4)</td>
<td>72% (18/25)</td>
<td>56% (5/9)</td>
<td>94% (16/17)</td>
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<tr>
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<td>D</td>
<td>30% (12/40)</td>
<td>18% (2/11)</td>
<td>15% (2/13)</td>
<td>5% (1/21)</td>
<td>90% (9/10)</td>
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<tr>
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<td>52% (28/54)</td>
<td>22% (4/18)</td>
<td>30% (3/10)</td>
<td>44% (4/9)</td>
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<td>27% (4/15)</td>
<td>32% (8/25)</td>
<td>0% (0/3)</td>
<td>67% (8/12)</td>
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<tr>
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<td>C</td>
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<td>21% (22/104)</td>
<td>42% (11/26)</td>
<td>18% (9/51)</td>
<td>65% (36/55)</td>
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<tr>
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<td>100% (4/4)</td>
<td>56% (5/9)</td>
<td>93% (14/15)</td>
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<td>20% (1/5)</td>
<td>50% (1/2)</td>
<td>44% (4/9)</td>
<td>100% (4/4)</td>
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<td>47% (91/195)</td>
<td>22% (38/176)</td>
<td>79% (210/266)</td>
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</tbody>
</table>

Alaska | D | 29% (2/7) | 0% (0/2) | 0% (0/1) | 40% (2/5) | 100% (1/1) | 29% (2/7) |
Arizona | B | 69% (25/36) | 0% (0/3) | 75% (3/4) | 56% (5/9) | 81% (13/16) | 11% (1/9) |
California | B | 67% (159/236) | 32% (14/44) | 63% (24/38) | 35% (6/17) | 83% (54/65) | 21% (10/48) |
Colorado | B | 73% (24/33) | 86% (6/7) | 25% (1/4) | 25% (3/12) | 75% (6/8) | 20% (6/30) |
Hawaii | C | 58% (7/12) | - (0/0) | 0% (0/2) | 25% (1/4) | 100% (1/1) | 20% (1/5) |
Idaho | B | 63% (5/8) | 50% (1/2) | 50% (1/2) | 0% (0/1) | 100% (2/2) | 29% (6/21) |
Montana | B | 67% (6/9) | - (0/0) | - (0/0) | 75% (6/8) | 100% (1/1) | 20% (9/46) |
Nevada | B | 69% (9/13) | 60% (3/5) | 0% (0/1) | 0% (0/3) | 67% (2/3) | 17% (1/6) |
New Mexico | C | 44% (8/18) | 33% (3/9) | 50% (1/2) | 36% (5/14) | 100% (2/2) | 23% (3/13) |
Oregon | A | 88% (23/26) | 0% (0/2) | 100% (2/2) | 80% (4/5) | 100% (7/7) | 25% (8/32) |
Utah | C | 60% (9/15) | 17% (1/6) | 100% (1/1) | 50% (3/6) | 100% (5/5) | 38% (5/13) |
Washington | A | 83% (33/40) | 50% (2/4) | 63% (5/8) | 67% (2/3) | 90% (9/10) | 29% (8/28) |
Wyoming | C | 50% (3/6) | 0% (0/1) | 75% (3/4) | 27% (3/11) | - (0/0) | 11% (2/19) |
WEST | B | 68% (313/459) | 35% (30/85) | 59% (41/69) | 41% (40/98) | 85% (103/121) | 22% (62/277) |

NATIONAL | B | 63% (1568/2489) | 26% (108/419) | 54% (192/356) | 37% (151/406) | 85% (597/699) | 22% (326/1500) |
## Table 2

**Prevalence of Palliative Care Health Care Professionals**

<table>
<thead>
<tr>
<th></th>
<th>ABHPM-Certified Physicians</th>
<th>Medicare Deaths per Certified Physician</th>
<th>Medicare Hospital Deaths per Certified Physician</th>
<th>Medicare Deaths per Certified ABHPM-Certified Advanced Practice Nurses</th>
<th>Medicare Hospital Deaths per Certified APN</th>
<th>NBCHPN-Certified Registered Nurses</th>
<th>Medicare Deaths per Certified RN</th>
<th>Medicare Hospital Deaths per Certified RN</th>
<th>Medicare Deaths (2005)</th>
<th>Medicare Deaths Occurring Within a Hospital (2005)</th>
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Table 2 Prevalence of Palliative Care Health Care Professionals (continued)

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<th>Medicare Deaths per Certified Physician</th>
<th>Medicare Hospital Deaths per Certified Physician</th>
<th>NBCHPN-Certified APN</th>
<th>Medicare Hospital Deaths per Certified APN</th>
<th>NBCHPN-Certified Registered Nurses</th>
<th>Medicare Deaths per Certified RN</th>
<th>Medicare Hospital Deaths per Certified RN</th>
<th>Medicare Deaths (2005)</th>
<th>Medicare Deaths Occurring Within a Hospital (2005)</th>
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Glossary

Here are some terms used throughout this report, along with others you are likely to encounter in similar publications.

**Allopathic medicine**
Also known as “conventional medicine,” the system of medical practice that treats disease by using remedies that produce effects different from those produced by the disease under treatment. MDs, for example, practice allopathic medicine.

**Hospice**
Hospice provides palliative care focused on terminally ill patients who are no longer seeking curative or life-prolonging treatments and who are expected to live for about six months or less. Hospice is provided through the Medicare hospice benefit and other payers, and can take place in the home, nursing home, hospital or at a stand-alone hospice.

**Hospital palliative care program**
Interdisciplinary medical team focused on symptom management, intensive patient-physician-family communication, clarifying goals of treatment and coordination of care across health care settings.

**Hospital types**

*For-profit hospitals:* Hospitals with fifty or more beds that are run by individuals, partnerships or corporations.

*Large hospitals:* Hospitals with 300 or more beds.

*Public hospitals:* Not-for-profit institutions run by a state, county, city, joint city-county, hospital district or authority, with fifty or more beds. (In this report, nongovernment, not-for-profit hospitals, such as those run by church-affiliated institutions, were excluded from this category.)

*Small hospitals:* Hospitals with fewer than fifty beds. Sole community provider (SCP) hospitals receive special designation by Medicare because they are located more than thirty-five miles from other hospitals, or they serve as the sole provider of health care services for a region due to limitations in local topography or prolonged severe weather conditions.
**Hospitalist**
A physician who is employed by the hospital and specializes in the care of hospitalized patients.

**National Consensus Project for Quality Palliative Care (NCP)**
A national consensus project that published formal definitions of palliative care in 2004 (*Clinical Practice Guidelines for Quality Palliative Care*), with a second edition released in 2009. The guidelines were intended to direct the development and structure of both new and existing palliative care teams; establish uniform definitions of the essential elements of palliative care; establish national goals for access to palliative care; promote performance measurement and quality improvement initiatives in palliative care services; and foster continuity of palliative care across settings (including home, hospital and hospice). The guidelines fall within eight defined domains of palliative care. (See [www.nationalconsensusproject.org](http://www.nationalconsensusproject.org).)

**National Quality Forum (NQF)**
A framework for preferred practices of providing quality palliative care, released in 2006. Practices are defined across the Institute of Medicine’s six dimensions of quality: safe, effective, timely, efficient, equitable and patient-centered. The NQF Framework used the clinical practice guidelines of the National Consensus Project for Quality Palliative Care as a starting point for identifying expectations and best practices in palliative care. (See [www.qualityforum.org/palliative](http://www.qualityforum.org/palliative).)

**Palliative care, palliative medicine**
Palliative care (pronounced pal-lee-uh-tiv) is specialized medical care for people with serious illnesses. It focuses on providing patients with relief from the symptoms, pain and stress of a serious illness—whatever the diagnosis. The goal is to improve quality of life for both the patient and the family. Palliative care is provided by a team of doctors, nurses and other specialists who work together with a patient’s other doctors to provide an extra layer of support. It is appropriate at any age and at any stage in a serious illness and can be provided along with curative treatment.

**Palliative care team, palliative care program**
An interdisciplinary, specialized medical team that provides palliative care in the hospital. The team works together with a patient’s own doctor and includes physicians, nurses and social workers. It may also include chaplains, massage therapists, rehabilitation experts, pharmacists, nutritionists and others.
The Center to Advance Palliative Care

www.capc.org
www.getpalliativecare.org

The Center to Advance Palliative Care (CAPC), established in 2000, is a not-for-profit national organization whose purpose is to provide health care professionals with the tools, training and technical assistance necessary to start and sustain successful palliative care programs in hospitals and other health care settings. The mission of CAPC is to increase the availability of quality palliative care services for people facing serious, complex illness.

Led by Diane E. Meier, MD, CAPC receives direction and technical assistance from Mount Sinai School of Medicine, New York City. CAPC also works in close collaboration with the National Palliative Care Research Center.

CAPC focuses primarily on the operational development of palliative care teams in hospitals, as most seriously ill patients require hospital care at one or more points during their illness. Because of the medical crises that often lead to hospitalization, hospitals are typically the places where planning for the next phase in the care continuum occurs.

CAPC is supported by funding from Archstone Foundation, Brookdale Foundation, Donaghue Foundation, the Emily Davie and Joseph S. Kornfeld Foundation, the John A. Hartford Foundation, Mill Park Foundation, the Olive Branch Foundation, Partnership for Palliative Care, the Robert Wood Johnson Foundation, the United Hospital Fund and the Y. C. Ho/Helen and Michael Chiang Foundation.

The National Palliative Care Research Center

www.npcrc.org

The mission of the National Palliative Care Research Center (NPCRC) is to improve care for patients with serious illness and address the needs of their families by promoting palliative care research. The NPCRC establishes priorities for palliative care research; develops a new generation of researchers in palliative care; and coordinates and supports studies focused on improving care for patients and families living with serious illness.

The NPCRC is led by R. Sean Morrison, MD, and is located in New York City at Mount Sinai School of Medicine. In collaboration with the Center to Advance Palliative Care, the NPCRC works to rapidly translate important research findings into clinical practice in order to improve the care received by both patients living with serious illness and their families.

The NPCRC was established in July 2005 with a grant from the Emily Davie and Joseph S. Kornfeld Foundation and has received subsequent funding from the Olive Branch Foundation, Brookdale Foundation, American Cancer Society, American Academy of Hospice and Palliative Medicine, Betty and Norman F. Levy Foundation, the Y. C. Ho/Helen and Michael Chiang Foundation, Hearst Foundations, National Institute on Aging, U.S. Cancer Pain Relief Committee, American Express Foundation, Mill Park Foundation, Hospice and Palliative Nurses Association, LIVESTRONG, the Atlantic Philanthropies and the Partnership for Palliative Care.