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A National Strategy For Palliative Care

ABSTRACT In 2014 the World Health Organization called for palliative care to be integrated as an essential element of the health care continuum. Yet in 2017 US palliative care services are found largely in hospitals, and hospice care, which is delivered primarily in the home, is limited to people who are dying soon. The majority of Americans with a serious illness are not dying; are living at home, in assisted living facilities, or in nursing homes; and have limited access to palliative care. Most health care providers lack knowledge about and skills in pain and symptom management, communication, and care coordination, and both the public and health professionals are only vaguely aware of the benefits of palliative care and how and when to access it. The lack of policy supports for palliative care contributes to preventable suffering and low-value care. In this article we outline the need for a national palliative care strategy to ensure reliable access to high-quality palliative care for Americans with serious medical illnesses. We review approaches employed by other countries, list the participants needed to develop and implement an actionable strategy, and identify analogous US national health initiatives to inform a process for implementing the strategy.

In 2014 the World Health Organization (WHO) called for standardized access to palliative care as a human right.¹ The resolution called on all governments to fund policy changes, clinician training, multisector partnerships, and support for family caregivers and communities to care for people with serious illnesses. Countries using national strategies² to attempt to improve access to high-quality palliative care include high-income nations such as Australia, Singapore, and the United Kingdom and low- to middle-income countries such as Georgia, Romania, and Uganda.³

However, as of 2017 palliative care remains difficult to access for the more than forty million Americans with serious illness and functional dependency.^{4,5} Furthermore, many US health professionals lack training in core palliative care

domains: the treatment of pain and other symptoms, communication about care priorities and options with patients and families and across settings, and care coordination. Additionally, most Americans are only vaguely aware of the benefits of palliative care and how and when to access it.⁶ Traditional fee-for-service incentives favor high-volume hospitals and office practices—especially diagnostic testing, procedures, and the physicians that deliver them. The time-intensive coordination, counseling, and complex medical management required to deliver high-quality palliative care cannot be supported by the volume incentives of fee-for-service medicine.

In the United States, palliative care's growth has been organic rather than strategic, with programmatic development and access driven by local champions and market forces—which has

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led to marked variation in access and quality. A comprehensive national strategy for palliative care—akin to the National HIV/AIDS Strategy⁷ or the National Alzheimer's Project Act (NAPA)⁸ in the United States—has not been enacted, despite public support for universal access to palliative care^{4,6} and a substantial body of evidence about its ability to improve value across diverse care settings.^{9–18}

We propose the creation of a national strategy for palliative care led by the federal government and supported by payers and regulators. The strategy would include defined structures and processes for palliative care programs, reimbursement schedules, quality and access standards, health care education, and investment in research.

What Is Palliative Care?

Palliative care is a team-based specialty that focuses on improving the quality of life and relieving the suffering of people living with serious illness, as well as their families.⁴ Provided by doctors, nurses, social workers, and chaplains, specialist-level palliative care treats pain and other distressing symptoms, helps patients and families understand their illness and treatment options, matches treatments to their informed goals, and coordinates care across settings.¹⁹ Primary- or generalist-level palliative care integrates palliative care elements into the care provided by all clinicians serving the seriously ill. Eligibility for palliative care should be determined by patient and family need and not by prognosis—an approach that has not yet been widely implemented.

When offered under the Medicare hospice benefit,²⁰ palliative care is limited by statute to people who agree to forgo Medicare coverage for “curative” disease treatment in return for Medicare reimbursement for hospice services, and who have certifications from two physicians that they will live for six months or less if their disease follows its usual course. Outside of hospice, palliative care is appropriate for patients with serious illnesses who are still benefiting from curative or life-prolonging treatment (for example, patients with leukemia), those who may live for several years with one or more serious illnesses (such as dementia and heart failure), and those with progressive and terminal disease (for example, advanced cancer).

In the United States, specialist-level palliative care is not readily available in all states. In seventeen states, more than 80 percent of hospitals with more than fifty beds report a palliative care team (Exhibit 1). However, in seven states, no more than 40 percent of hospitals with more

than fifty beds report a palliative care team.²¹ Despite evidence of the value of palliative care,^{9,11–16} the majority of people who are seriously ill but are neither predicted to die soon nor hospitalized have little access to such care. Instead, they receive health care uninformed by palliative care principles in office practices and clinics, at home, in nursing homes, or in assisted living facilities.²²

What Are Palliative Care's Outcomes?

Palliative care is associated with a growing body of evidence supporting its ability to achieve the Triple Aim: improving the patient experience of care, improving health, and reducing unnecessary medical interventions and their associated costs.^{9,11–18} Randomized controlled trials with people who have cancer^{12,23} or advanced lung disease¹⁷ suggest the possibility of improved survival associated with palliative care provided concurrently with usual treatment, compared to receiving usual care only. Despite common physician misconceptions, no study has associated palliative care with increased mortality in comparison to traditional care. A systematic review of forty-six high-quality studies, predominantly from the United States, demonstrated consistent and significant reductions in hospitalization and total spending in association with palliative care services.¹⁸

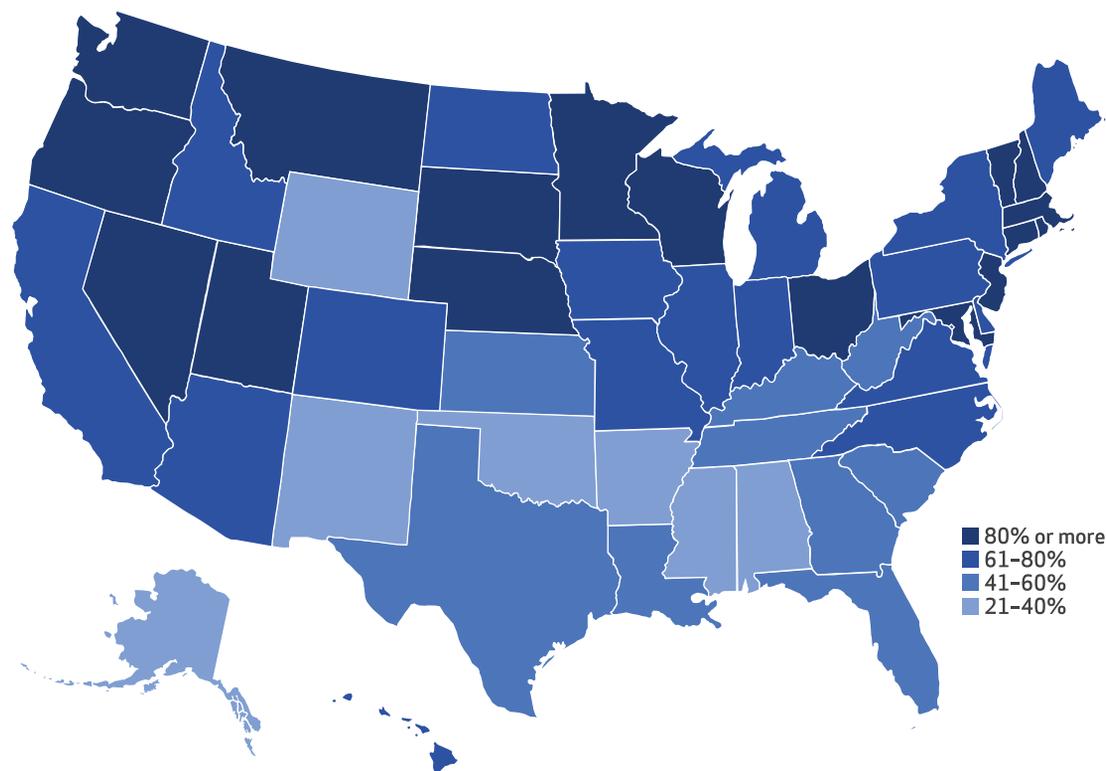
Who Benefits From Palliative Care?

Most people with serious illnesses and associated high health care spending are not in their last year of life.²⁴ Among the 5 percent of patients who annually account for roughly 50 percent of all health care spending,^{5,24} only 11 percent, in retrospect, incurred these costs in the last year of life.²⁵ About half of the patients in the costliest 5 percent have one-time high costs but go on to recover, and their subsequent health spending regresses to the mean in the following year. An example of this group is people who undergo a complicated surgical procedure.

The remaining 40 percent of the costliest 5 percent of patients are characterized by one or more of the following: multimorbidity; functional or cognitive impairment, or both; and one or more serious illnesses—and incur high costs year after year. Most of the people in this group live at home or in nursing homes and are ineligible for hospice until the very end of their lives. Although hospitalized frequently, they spend most of their time out of the hospital^{5,24,25} with limited access to palliative care. This group reports high levels of functional dependency and symptom

EXHIBIT 1

Access to hospital palliative care in the United States, by percentage of hospitals with more than 50 beds reporting palliative care services in each state, 2015



SOURCE Authors' analysis of data for 2014 from the American Hospital Association Annual Survey and the Center to Advance Palliative Care's National Palliative Care Registry; and from Morrison RS, Meier DE. America's care of serious illness (see Note 21 in text).

distress, including pain and depression; their families bear the financial and social burdens of caregiving; and preventable symptom crises result in reliance on 911 calls, emergency departments, and hospitals. Palliative care programs have been shown to improve all of these outcomes.¹⁹

The Development Of Palliative Care In The United States

Palliative care in the United States (outside of hospice) was developed in the mid-1990s within academic medical centers and supported by major philanthropic investments.²⁶ These investments, which totaled over \$200 million, helped establish a new American Board of Medical Specialties subspecialty^{27,28} and a new nursing certification program;²⁸ create palliative care programs in the majority of US hospitals²¹ and new professional journals and textbooks; and increase awareness among policy makers and the public at large of palliative care's positive impact on value.^{29,30}

The absence of government oversight of and support for palliative care initiation and dissemination has resulted in variable quality and access. The presence of palliative care in a community depends not on population need, but rather on accidents of geography,²¹ the availability of effective clinical and philanthropic leaders, and the presence of an academic teaching hospital. As shown by the 2015 state-by-state report card (Exhibit 1) of the Center to Advance Palliative Care and the National Palliative Care Research Center,²¹ the prevalence of hospital palliative care programs in southern states and at for-profit hospitals, safety-net hospitals, and small and sole-community-provider hospitals is well below the national average. Reliable access to palliative care that meets national standards as a core element of quality in all settings will require government, regulatory, and payer support and involvement.

Barriers To Accessing Palliative Care

Barriers to palliative care access in the United States also exist in most high-income nations

and occur in five domains: lack of public and professional awareness of palliative care's benefits; workforce shortages and inadequate training; insufficient organizational capacity, due in part to misaligned (fee-for-service) payment programs; lack of regulatory requirements, oversight, and accreditation standards to ensure access and quality; and an inadequate evidence base to guide safe and effective practice.

LACK OF AWARENESS The misperception among doctors and other health professionals that palliative care is appropriate only at the end of life and the belief that patients will react negatively and lose hope if palliative care is discussed prevent many patients from getting the relief they need.⁶ While physicians have misperceptions about palliative care, many patients simply do not know about it. A recent national survey revealed that only 8 percent of Americans reported being knowledgeable or very knowledgeable about palliative care.⁶

WORKFORCE SHORTAGES AND INADEQUATE TRAINING The number of palliative care specialists falls short of what is necessary to serve the current population.³¹ The American Board of Medical Specialties approved subspecialty physician training in palliative medicine relatively recently, in 2008, and financial support for such training relies predominantly on philanthropy rather than Medicare-funded graduate medical education dollars—a result of the cap on Medicare-funded training slots in the Balanced Budget Act of 1997.³² Similar shortages exist across the other palliative care disciplines of nursing, social work, and chaplaincy.

It is unrealistic to expect that the specialist workforce will ever be large enough to meet the needs of all seriously ill Americans. Front-line clinicians' knowledge and skills must be strengthened if palliative care is to be available to everyone who could benefit from it. US clinicians receive little to no training in palliative care,³³ including skilled communication with patients and families in the context of serious illness, safe and effective symptom management, and psychosocial assessment and support. Ensuring that all clinicians are trained in these competencies is essential to standardize access to palliative care.

Lastly, most of the day-to-day care for people with serious illnesses is provided by family members and other informal caregivers, who are expected to advocate for their loved ones' preferences and interests, administer medications and other treatments, coordinate care among specialists and settings, and do so in addition to their other work and family responsibilities—despite little or no training and support.^{34,35} Adequate training, supervision, and support of all

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members of the care team, including family caregivers, are needed.

INSUFFICIENT ORGANIZATIONAL CAPACITY AND MISALIGNED PAYMENT Palliative care capacity and delivery models are largely unavailable for patients living at home, in nursing homes, or in rural areas. Palliative care programs in hospitals are often stretched to capacity because of staffing constraints^{36,37} and are obligated to give priority to the most complex patients or those closest to the end of life, thus limiting access for many people who would benefit. Major barriers to palliative care in community settings are the lack of Medicare payment (with the exception of hospice) for personal care (such as home health aides), home medical services (such as nursing, social work, and rehabilitation supports) beyond time-limited episodes of postacute care, and team-based care, and regulatory and legal constraints inhibiting the use of telemedicine.³⁸

The value-based incentives now influencing risk-bearing entities (such as Medicare Advantage plans, Medicaid managed care plans, and accountable care organizations) have recently begun to increase the use of palliative care models, but access falls short of the population need. Recent multi- and all-payer initiatives launched by the Centers for Medicare and Medicaid Services (CMS), including the Center for Medicare and Medicaid Innovation, are promising examples of payer support for insurance design matched to the needs of seriously ill beneficiaries.³⁹ For example, the Medicare Advantage Value-Based Insurance Design Model, supported by the bipartisan Creating High-Quality Results and Outcomes Necessary to Improve Chronic (CHRONIC) Care Act reintroduced in the Senate in 2017, tests “a model of Medicare Advantage value-based insurance design that would allow Medicare Advantage plans the option to propose and design benefit structures that vary benefits, cost-sharing, and supplemental benefits offered to enrollees with specific chronic diseases.”⁴⁰ Also, the multipayer Comprehensive Primary Care Plus (CPC+)⁴¹ model tests the ability of

Research funding in other areas of health care dwarfs that in palliative care.

primary care practices to build capabilities (such as 24/7 phone availability) to improve care, with payments designed to allow “greater cash flow and flexibility for primary care practices to deliver high quality, whole-person, patient-centered care and lower use of unnecessary services that drive total costs of care.”⁴² Insurance designs allowing payment for services to be matched to the requirements of high-need beneficiaries could include, for example, payment for 24/7 phone access, home health aides, family counseling, home delivery of meals, and transportation.

LACK OF REGULATORY REQUIREMENTS, OVERSIGHT, AND ACCREDITATION STANDARDS In some other areas of health care, the oversight of quality is driven by federal- and state-level regulatory and accreditation requirements. For example, hospitals must be accredited by the Joint Commission (or other deemed entity) to receive Medicare payments, and dialysis units must be certified by Medicare to receive payment.⁴³ In contrast, the only quality oversight programs for palliative care are a new Joint Commission certification for community-based programs and a Joint Commission advanced certification program for hospital-based programs, both voluntary.⁴⁴

Intensive efforts to contain the costs of the seriously ill are accompanying the shift to value-based payment. They carry risks for undertreatment, poor quality of care, unsafe environments, and excessive out-of-pocket expenditures. Consumer protections are needed to reduce such risks.

Accountability depends on certification and accreditation programs that set standards and conduct reviews to verify compliance; the development of new Medicare and Medicaid conditions of participation for provision of palliative care services, with regulatory surveillance; transparent performance data, including public reporting that provides comparative data on patients’ experiences and outcomes, staffing ratios, care processes, and use of resources; and the development of quality metrics linked to payment that are reliable, valid, actionable,

meaningful to patients and families, and appropriate in the context of complex illnesses in diverse settings. These components would help ensure that people with serious illnesses have reliable access to high-quality care at a reasonable cost.

INADEQUATE EVIDENCE BASE Research funding in other areas of health care dwarfs that in palliative care. Studies have found that less than 0.2 percent of the annual budget of National Institutes of Health (NIH) supported palliative care research.^{45,46} Several NIH institutes have never funded research in palliative care, despite their focus on common serious illnesses such as end-stage renal disease. As a result, the knowledge base to support pain and symptom management, communication skills, care coordination, and optimal care models is inadequate.

Consequences Of The Lack Of A National Strategy

The absence of a national strategy has consequences that are visible in a range of areas. Despite the recent CMS decision to reimburse physicians and other providers for discussing advance care planning with their patients,⁴⁷ physicians do not have to demonstrate core competencies in this complex procedure to be reimbursed. These competencies are akin to those required of a surgeon performing a procedure such as an appendectomy—a procedure that is taught, practiced, and supervised, after which the surgeon’s performance is assessed for quality and safety before he or she is allowed to perform it independently. Core clinician competencies could be ensured by payers such as CMS; accrediting bodies such as the Joint Commission; or educational groups such as the Liaison Committee on Medical Education, which accredits medical schools, or the Accreditation Council for Graduate Medical Education, which accredits graduate medical education programs.

Similarly, while multiple entities have developed palliative care training curricula,⁴⁸ there are minimal state licensing or medical educational accreditation standards requiring providers to demonstrate competency in palliative care.

Additional consequences are variation in quality and access to palliative care at the levels of both health systems and providers,³⁷ confusion over whether and how best to measure and report quality of care for seriously medically ill people, a lack of confidence among the public that doctors and nurses have the necessary clinical competencies, and the continuation of well-documented overuse of low-value and burdensome medical interventions among patients

who cannot benefit from them.⁴⁹

Pressures to reduce spending are shifting reimbursement from fee-for-service models toward value-based models with shared risk.⁵⁰ Consequently, community-based palliative care services are increasingly contracting with risk-bearing payers to serve the populations with the highest needs, with no standards, quality requirements, or regulatory oversight aside from the basic requirements of health professional licensure. Because these services focus on the sickest and costliest minority of Americans least likely to be able to advocate for themselves, ensuring the existence of national quality standards, adequate clinician training, and regulatory oversight to prevent inappropriate undertreatment is particularly urgent.

Core Elements Of A National Strategy

The experience of other high-income countries offers insights into themes associated with national palliative care strategy efforts. For summaries of international strategies and citations to sources, see online Appendix 1.⁵¹

A national palliative care strategy endorsed in 2000 by the Australian Health Ministers' Advisory Council committed the government, service providers, and community-based organizations to implementing consistent palliative care policies and services. It provided the framework for collaboration between state and national governments to ensure funding, policy making, planning, and service delivery directed toward shared goals. The strategy was updated in 2010 to address needs for improved awareness, appropriateness, and effectiveness of service delivery, leadership, and governance, and capacity in the national health system.

The 2001 New Zealand palliative care strategy was the culmination of a two-year project that included literature searches, needs analyses, surveys of palliative care providers, discussions with a variety of stakeholders (including a Maori working group), public comments on draft documents, and twelve public meetings and focus groups around New Zealand. The strategy addressed public awareness, workforce gaps, infrastructure, and research and included a ten-year commitment of government funding. An independent review eight years into the plan highlighted progress toward meeting workforce and quality requirements but made a series of recommendations to address remaining challenges. Subsequent audits noted gaps in access to community-based palliative medicine physicians, geographic and ethnic disparities, limited palliative care in undergraduate medical and

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nursing school curricula, and unreliable after-hours coverage. In response, the government allocated NZ\$76.1 million to address these gaps.

In both countries, factors correlated with efforts to improve access to palliative care included the broad engagement of senior policy makers in strategy and policy development. Countries where guidelines have been created by professional societies in isolation from policy makers appear to have had less success. Examples of these countries are Canada, Singapore, and the United States.

Multifaceted strategies that address the main barriers to access and quality and involve key constituents, including policy makers, have resulted in supportive legislation and new resource allocation. In New Zealand, monitoring and accountability via regular planned audits were developed in an effort to move the country's efforts forward after a slow start. A national system of performance reporting using standardized measures of access, patient experience, outcomes, and cost has characterized Australia's national strategy. Finally, substantial and sustained public investment via government funding for palliative care services, education, training, and research have been central to strategies in Australia, Ireland, New Zealand, Spain, and the United Kingdom.

Steps Forward

Health policy in the United States is driven by a complex patchwork of public and private payers, accreditation and licensing entities, and federal and state regulators. However, the federal government plays a critical role as the largest payer, regulator, arbiter of coverage, research funder, service provider (through the Veterans Health

Administration and the Department of Defense), and overseer of quality. Completing the health care policy quilt are state health departments that license clinicians, regulatory and accrediting bodies (such as the Joint Commission), and organizations responsible for certifying clinician education and training (such as the Liaison Committee on Medical Education and the Accreditation Council for Graduate Medical Education).

As a result of this complex patchwork, there is no single US entity that oversees all aspects of health care. To succeed, a palliative care strategy will require federal leadership in conjunction with a public-private, multistakeholder partnership. The Department of Health and Human Services (HHS) is a logical home for a US palliative care strategy, given its experience and success in developing several national strategies. Examples include a national effort to reduce health care-associated infections, a process initiated by Michael Leavitt (HHS secretary in the administration of President George W. Bush) that achieved a 50 percent reduction in central line-associated infections.⁵² The Office of National AIDS Policy was established under President Bill Clinton⁷ and resulted in a national strategy that yielded significant improvements in survival and quality of life among people with HIV. NAPA was initiated by bipartisan legislation in 2010, and required the HHS secretary to establish the National Alzheimer's Project.⁸

Each of these initiatives involved multiple stakeholders, including a federal interagency working group; government and commercial payers; private-sector philanthropy; regulatory and accrediting bodies; consumer, disease, and health profession organizations; and public and private research funders. (For a list of proposed participants in a national palliative care strategy, see the Appendix.)⁵¹ There has also been consistent bipartisan support for improving value in health care, as shown by the bipartisan commitment to the Medicare Access and CHIP Reauthorization Act of 2015 (MACRA),⁵³ the CHRONIC Care Act,⁴⁰ the Palliative Care and Hospice Education and Training Act,⁵⁴ and the work of the Bipartisan Policy Center.⁵⁵ Bipartisan commitment to replacing fee-for-service payment in

health care with value-based payment creates an opportunity for the needed government leadership through either legislation or executive action. The Appendix provides a logic map for such action.⁵¹

Conclusion

We believe that the time is ripe for the development of a US national strategy for palliative care. National, regional, and local private-sector investments have established the foundational capabilities for success, including quality measurement,^{56–58} training curricula,^{33,48} scalable advance care planning initiatives,^{59,60} model development and testing,^{9,13} and a growing body of evidence.^{16,61} Policy^{21,22} can broaden the focus of palliative care for the seriously ill beyond health systems and into homes and communities, where patients prefer to be and where care has been demonstrated to be of high quality and lower cost.^{9,10} A national strategy could address existing gaps in access, workforce training, accountability, financing, and the knowledge base. The goal would be to rebalance medical care, moving from its traditional exclusive focus on disease treatment to include whole-person and family care informed by palliative care principles.

The development of a national palliative care strategy should be led by HHS, involve key stakeholders, and include entities that can implement the strategy. As was the case with NAPA⁸ and other national health strategies, money will be necessary to drive implementation and sustain national and cross-sector attention. All of these steps are achievable, building on the national growth in access to palliative care over the past two decades in the United States and a broad bipartisan consensus on the need to improve quality of care while controlling unnecessary spending. We anticipate that matching treatments to patients' top priorities and goals, enhancing caregiver support, averting preventable crises, and reducing unnecessary hospitalizations and emergency department visits will result in savings that will rather quickly exceed the needed investments. ■

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