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Accountability For Quality In The Care Of People Living With A Serious Illness: The National Consensus Project Clinical Practice Guidelines For Quality Palliative Care, 4th Edition

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Health care spending is logically concentrated on the sickest and most complex patients in the U.S., with the [top 5% of spenders accounting for nearly 60% of all healthcare costs](#). Contrary to what many believe, [only 11% of these spenders are in the last 12 months of life](#). The remainder of the costliest 5% are either one-time high spenders (49%) whose health improves, or chronically ill year-over-year high spenders (40%). As a result, membership and prognoses in the highest spending group are neither predictable nor consistent over time. Additionally, in spite of high per capita spending, [multiple studies](#) suggest that this population routinely receives care of low quality, characterized by poor communication between patients, families and clinicians, lack of coordination over time and across settings, high levels of symptom distress, financial and family caregiver burden, and low levels of satisfaction. On October 31, 2018, the [National Coalition for Hospice and Palliative Care](#) released a new set of quality guidelines for delivery of palliative care to people living with serious illness, in an effort to standardize the elements of quality health care for people living with a serious illness.

Palliative Care

In the context of a growing population of people of all ages living for many years with serious chronic conditions, spread of new care models and new skills organized around the dominant needs of this group are necessary. In the last decade, accumulating evidence demonstrates the value of palliative care approaches in terms of both improved [quality and satisfaction](#), and greater [efficiency](#) of care.

[Palliative care](#) is a relatively recent development in the United States, becoming a medical subspecialty in 2006. Beneficial at any stage of a serious illness, palliative care is an interdisciplinary care delivery system designed to anticipate, prevent, and manage physical,

psychological, social, and spiritual suffering to optimize quality of life for patients, their families and caregivers. Palliative care can be delivered in any care setting through the collaboration of many types of care providers. Through early integration into the care plan of seriously ill people, palliative care improves quality of life for both the patient and the family.

The field grew out of the hospice movement, replicating its patient-centered approach to care but departing from its statutory eligibility requirements that restrict hospice to people very likely to die in less than 6 months and who are also willing to give up insurance coverage for disease treatment. It differs from the usual practice of medicine in its wholistic focus on the human experience, including spiritual aspects of meaning and purpose, practical issues like safe housing and access to food and transportation, and support for family caregivers. Since most people with a serious illness are not near the end of life and are continuing to want and to benefit from disease treatments, palliative care enables support for quality of life for patients and families throughout the (often long) course of a serious illness. To identify the population of patients and caregivers who need primary (delivered by all clinicians) or specialist level palliative care services, a serious illness is **defined** as “a health condition that carries a high risk of mortality AND either negatively impacts a person's daily function or quality of life, OR excessively strains their caregivers.”

While hospice has long been available to support care of the dying, in the last 15 years palliative care has expanded rapidly, becoming available at **more than 90% of large hospitals** and more recently developing in **home, office, and long-term care settings**. Community-based programs have been initiated by hospices delivering non-hospice palliative care, hospitals, health systems, and multi-state companies in a broad range of settings including homeless shelters, dialysis units,

safety net hospitals, and cancer centers. Given the recent evolution of these service models, it is perhaps not surprising that there is a high degree of variability in delivery models, payment models, and access, as well as [variability in quality](#).

Practice Standards

In an effort to promote standardization and consistency of care delivery, 16 palliative care organizations developed a set of consensus guidelines for quality palliative care. The first edition was published in 2003, and the [4th and most recent edition](#) was published on October 31, 2018 with major support from the Gordon and Betty Moore Foundation, and contributions from the John A. Hartford Foundation, the Stupski Foundation, and the Gary and Mary West Foundation. The guidelines have informed the work of national accrediting and quality organizations, including the National Quality Forum's [National Framework and Preferred Practices for Hospice and Palliative Care Quality](#), The Joint Commission's certification programs for [specialist level palliative care](#), and recently launched or planned certifications from other accrediting bodies including [DNV](#) and [CHAP](#).

What's Different About The New Edition Of The National Consensus Project For Quality Palliative Care Guidelines?

The 4th Edition calls for delivery of palliative care for all people living with serious illness, regardless of diagnosis, prognosis, care setting, or age, and for the first time calls on all health professionals to improve care during serious illness. To achieve this objective requires two changes. First, clinicians with palliative care knowledge and skills must be available in all care settings where patients seek care, and since the

majority of people with serious illness are neither dying (and therefore not hospice-eligible) nor hospitalized, clinicians must be able to deliver palliative care to people everywhere- in their homes, in their doctors' offices, and in long term care settings. At present, palliative care services are reliably available in most hospitals and, for the dying, through hospice, but not yet in other settings where people living with serious illness receive care (home, office, long term care). Second, deployment of a palliative care approach (quality of life focused care concordant with patient goals) must become the responsibility of all front-line clinicians serving people with serious illness, including primary care practices, specialty practices, and setting-specific staff such as hospitalists, nursing home clinicians, and clinic staff. This will require investment in education of mid-career clinicians, since most did not gain palliative care knowledge and skill while in training as well as quality standards ensuring adequate staff competencies. The new Guidelines focus on eight domains for quality (including appropriate structures and processes of care; physical; psychological; social; spiritual; and cultural aspects of care; care near the end of life; and ethical and legal aspects of care) and provide a series of case studies on how all clinicians can collaborate to implement them in the real world of resource constraints and limited access to specialist level palliative care teams.

That palliative care is widely recognized for its impact on improving value is evidenced by endorsement of the 4th Edition by more than 80 major health care organizations in the United States, including, for example, the American Board of Internal Medicine, the American Nurses Association, and the Accountable Care Learning Collaborative and many [others](#). Also notable is the broad range of health care disciplines developing and endorsing the Guidelines, and working within and outside of specialist level palliative care services.

Implementing The New Guidelines

There is little debate about the impact and value of palliative care. The big challenges are in the questions of what and how. The NCP Guidelines provide a roadmap for the healthcare industry- what needs to be done to ensure high value care for people living with serious illness and their families; and technical assistance on how to implement these strategies. Despite the consensus on the need, the value, and the components, we are a long way from reliable access to quality care during serious illness in this country. What will it take for palliative care to become standard of practice for all patients and families who can benefit?

Work on driving accountability for delivery of high-quality palliative care in the U.S. is underway through the [Serious Illness Quality Alignment Hub](#), led by the Center to Advance Palliative Care and the National Quality Forum, also with funding from the Gordon and Betty Moore Foundation. The project is investigating the feasibility of integration of palliative care standards and requirements into accreditation, regulation, star rating programs, value-based payment models, and conditions of participation. The aim is to move beyond the current status quo - wherein capacity constrained palliative care specialty practices serve a limited number of settings and populations - to a future where our most vulnerable patients and their families can come to rely on access to quality palliative care everywhere.

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