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# The National Agenda for Quality Palliative Care: The National Consensus Project and the National Quality Forum

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**Abstract**

*The release in 2007 of the National Quality Forum (NQF) preferred practices is a significant advance in the field of palliative care. These NQF preferred practices build on the clinical practice guidelines for palliative care developed by the National Consensus Project (NCP). The NQF is dedicated to improving the quality of American health care, and their focus on palliative care recognizes its growing place within the broader scope of health care. This article reviews the work of both the NCP and NQF and presents the domains and preferred practices that should guide quality improvement efforts in hospice and palliative care.*

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**Key Words**

*Palliative care*

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**Introduction**

In 2004, the National Consensus Project (NCP) for Quality Palliative Care made a major contribution to advancing the field through the publication of the Clinical Practice Guidelines for Palliative Care.<sup>1,2</sup> Building on the

NCP guidelines, in 2007 the National Quality Forum (NQF) released a set of preferred practices for palliative care. As the NQF is the nation's major private-public partnership responsible for identifying and approving evidence-based quality measures linked to reimbursement, the NQF framework represents a major advance for the field of palliative care.<sup>3</sup> The purpose of this article is to describe the significance of this advance to the field and to outline the resulting opportunities and challenges necessary to legitimize and sustain the field in the wake of these events.

### *The NCP for Quality Palliative Care*

The NCP began in 2001 as a consortium of four key national palliative care organizations. This included the American Academy of Hospice and Palliative Medicine (AAHPM), the Center to Advance Palliative Care (CAPC), the Hospice and Palliative Nurses Association (HPNA), and the National Hospice and Palliative Care Organization (NHPCO). With funding from the Robert Wood Johnson Foundation, these organizations came together to develop a consensus on what characteristics define quality for palliative care. The goal was to promote the growth and development of clinical programs that encompass the highest quality practices to guide the work of palliative care professionals. The process involved exhaustive review of the literature, 18 months of monthly conference calls, and development of a series of iterative drafts of a consensus document.

The mission of the NCP is "To create a set of voluntary clinical practice guidelines to guide the growth and expansion of palliative care in the United States."<sup>1</sup> The NCP recognized that these guidelines were by necessity voluntary because the provision of palliative care services is not yet a requirement for accreditation or for licensure. However, the NCP also recognized that the rapid growth in number and type of palliative care programs in health care settings across the country mandated a shared set of norms or standards so that patients could come to expect consistently high-quality services wherever they might live or seek care. This observation is affirmed by a report by CAPC that there are now over 2,000

hospitals in the United States with existing or developing palliative care programs.<sup>4</sup>

The NCP guidelines were developed to describe the kind of palliative care that could be provided for a wide range of patient populations, including those with congenital injuries or conditions, acute serious life-threatening illnesses, and progressive chronic conditions. The population appropriate for palliative care also includes those with chronic and life-limiting injuries from accidents or other forms of trauma as well as those who are seriously or terminally ill.

Although the field of palliative care in hospital, academic, and nursing home settings has developed rapidly in the United States over the past few years, it builds upon our 30-year tradition of hospice as a largely home-based interdisciplinary system of end-of-life care. Palliative care is the broad umbrella that encompasses health care focused on comfort and reduction of symptoms, support for communication between patients, families, and health professionals, and assurance of continuity of care across settings versus a purely disease-focused model of life prolongation and attempted cure of disease. The NCP recognizes that there are many models of palliative care delivery, including consultation services, dedicated inpatient units, combined hospice and palliative care programs; and hospice or palliative care is provided across a wide range of settings, including home, long-term care facilities, hospitals and outpatient practices.

### *The NCP Domains*

The NCP developed a framework that identified eight domains of quality palliative care.<sup>4</sup> The domains are listed in Table 1, with the key elements described within the guidelines. As illustrated in this table, the NCP guidelines address the structure and process of care in an effort to provide guidance for newly developing programs as well as to strengthen existing programs. For example, the guidelines call for an interdisciplinary team of palliative care professionals, encourage these professionals to obtain advanced training and certification in palliative care, point out the importance of bereavement

*Table 1*  
**Domains and Recommendations from the NCP Guidelines**

NCP Domain	Recommendations
Domain 1: Structure and Processes of Care	Comprehensive interdisciplinary assessment of patient and family Addresses identified and expressed needs of patient and family Interdisciplinary team consistent with plan of care Education and training Emotional impact of work Team has relationship with hospices Physical environment meets needs of patient and family
Domain 2: Physical Aspects of Care	Pain, other symptoms, and treatment side effects are managed using best practices Team documents and communicates treatment alternatives permitting patient/family to make informed choices Family is educated and supported to provide safe/appropriate comfort measures to patient
Domain 3: Psychological and Psychiatric Aspects of Care	Psychological and psychiatric issues are assessed and managed Team employs pharmacologic, nonpharmacologic, and complementary therapies as appropriate Grief and bereavement program is available to patients and families
Domain 4: Social Aspects of Care	Interdisciplinary social assessment Care plan developed Referral to appropriate services
Domain 5: Spiritual, Religious, and Existential Aspects of Care	Assesses and addresses spiritual concerns Recognizes and respects religious beliefs—provides religious support Makes connections with community and spiritual/religious groups or individuals as desired by patient/family
Domain 6: Cultural Aspects of Care	Assesses and aims to meet the culture-specific needs of patients and families Respects and accommodates range of language, dietary, habitual, and ritual practices of patients and families Team has access to/uses translation resources Recruitment and hiring practices reflect cultural diversity of community
Domain 7: Care of the Imminently Dying Patient	Signs and symptoms of impending death are recognized and communicated As patients decline, team introduces or reintroduces hospice Signs/symptoms of approaching death are developmentally, age, and culturally appropriate
Domain 8: Ethical and Legal Aspects of Care	Patient's goals, preferences, and choices are respected and form basis for plan of care Team is aware of and addresses complex ethical issues Team is knowledgeable about relevant federal and state statutes and regulations

support after the patient's death, and identify the different developmental and family needs of children receiving palliative care. This creates an opportunity to ensure both more uniformity within the practice of palliative care and a more uniform standard for the provision of palliative care for consumers, payers, and accrediting bodies.

Five domains encompass the four aspects of comprehensive and multidimensional care, including the physical, psychological/psychiatric, social, and spiritual/religious. The guidelines also address key elements of palliative care by acknowledging the very important influence culture has on serious illness and death. Another domain recognizes that expert palliative care of the seriously ill or dying patient becomes even more important as death

is imminent. The last domain listed recognizes those ethical and legal aspects of care that will influence clinical outcomes.

The NCP guidelines were released in April 2004 and, over the following months, received widespread recognition and attention. Dissemination occurred via the Web site ([www.nationalconsensusproject.org](http://www.nationalconsensusproject.org)), professional meetings and presentations, direct mail, e-marketing, and publications in the trade media and journals. Palliative care leaders were eager for clinical practice guidelines to guide the structures and processes of new programs, and to promote uniformity and elevate the standard of care provided. For the last two years, the NCP has continued its collaborative work and has focused on broad dissemination of the guidelines. The NCP guidelines also

have been used extensively by membership and professional organizations as a framework for technical assistance to members, educational curriculum, and research priorities. Table 2 includes a list of organizations that have endorsed the guidelines.

## NQF

The NQF is a broad-based nonprofit “organization of organizations” tasked with the mission of developing ways to improve the quality of American health care. The NQF effects this goal through endorsement of consensus-based national standards for measurement and public reporting of health care performance data that provide meaningful information about

whether care is safe, timely, beneficial, patient-centered, equitable, and efficient. Established as a public-private partnership, the NQF has broad participation from all parts of the health care system, including national, state, regional, and local groups representing consumers, public and private purchasers, employers, health care professionals, provider organizations, health plans, accrediting bodies, labor unions, supporting industries, and organizations involved in health care research or quality improvement. Together, the members of the NQF work to promote a common approach to measuring health care quality and fostering system-wide capacity for quality improvement. More information can be found at <http://www.qualityforum.org>.

The NQF utilizes a five-step process: consensus standard development, widespread review, member voting and council approval, Board of Directors action, and subsequent evaluation. The NQF process is characterized by openness, balance, due process, consensus, and appeals mechanisms, and approval subsequent to this rigorous process is an accepted means of identifying standards appropriate for reimbursement by major payers. The implications of endorsement by the NQF for the field of palliative care are profound and include legitimacy in the eyes of policy makers; legitimacy, stable reimbursement structures, and coverage implications for payers; and a first step toward development of actionable measures for quality improvement, benchmarking, accreditation, and public reporting.

In recognition of the importance of engagement of the NQF to achieve these goals, NCP leaders approached the NQF to request their review and endorsement of the clinical practice guidelines. Again, with support of the Robert Wood Johnson Foundation, the NQF agreed to convene a review committee to evaluate and modify the NCP guidelines to fit the NQF approach to developing a framework. The process was greatly facilitated and expedited by the previously accomplished development of consensus guidelines, a process that did not have to be repeated.

Most importantly, the NQF accepted and endorsed the definition of palliative care as offered by the NCP. The NCP definition for palliative care stipulates that “Palliative care is both a philosophy of care and an organized,

*Table 2*  
**Organizations Endorsing the NCP Clinical Practice Guidelines**

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Academy of Medical-Surgical Nurses
American Academy of Ambulatory Care Nursing
American Academy of Pediatrics
American Alliance of Cancer Pain Initiatives
American Association of Colleges of Nursing
American Association of Critical Care Nurses
American Association of Neonatal Nurses
American Association of Spinal Cord Injury Nurses
American Board of Hospice and Palliative Medicine
American College of Nurse Practitioners
American College of Surgeons
American Geriatrics Society
American Medical Directors Association
American Nephrology Nurses Association
American Pain Foundation
American Pain Society
American Society for Bioethics and Humanities
American Society for Pain Management Nursing
American Society of Law, Medicine, and Ethics
American Society of Pediatric Hematology/Oncology
American Society of Plastic Surgical Nurses
Association of Nurses in AIDS Care
Association of Pediatric Oncology Nurses
CAPC
Dermatological Nurses Association
Emergency Nurses Association
Hospital Corporation of America
International Association for Hospice and Palliative Care
National Association of Directors of Nursing Administration for Long-Term Care
National Association of Social Workers
National Association of Clinical Nurse Specialists
National Hospice and Palliative Care Coalition (including AAHPM, HPNA, and NHPCO)
Oncology Nursing Society
Sigma Theta Tau (Honorary Nursing Society)
Society of Critical Care Medicine
Society of Internal General Medicine
Society of Pediatric Nurses
Supportive Care Coalition: Pursuing Excellence in Palliative Care

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highly structured system for delivering care. The goal of palliative care is to prevent and relieve suffering and to support the best possible quality of life for patients and their families, regardless of the stage of the disease or the need for other therapies. Palliative care expands traditional disease-model medical treatments to include the goals of enhancing quality of life for patients and family members, helping with decision making, and providing opportunities for personal growth.”<sup>1</sup>

The NQF also opted to accept the NCP domains for its framework structure and then proceeded to write preferred practices or actions that could be taken to operationalize the NCP guidelines in clinical settings and whose implementation could be measured and evaluated. For example, these preferred practices include use of an interdisciplinary palliative care team, 24-hour-per-day, seven-days-per-week access to palliative care, staff training, support, and credentialing.<sup>3</sup>

### ***NQF Best Practices***

The NQF framework identifies 38 best practices across the eight domains of the framework. These best practices are evidence based and when evidence was limited, expert opinion was proffered by the NQF framework committee. The best practices apply to both hospice and palliative care settings. These best practices are intended to set goals and stimulate development of valid performance measures. Table 3 includes a list of the NQF preferred practices relating to the eight NCP domains.

### ***Next Steps: Measurement and Evaluation***

Release of the NQF preferred practices and framework is an important advance in the field of palliative care. Although the field of hospice has standards of care, including the Conditions of Participation required for Medicare certification, the palliative care field has developed rapidly without a clear roadmap or uniform approaches to measuring outcomes, leading to substantial variability among programs. Consumers, therefore, are not able to rely on access to consistent and high-quality services. The guidelines developed

by the NCP and the subsequent translation of work into the broader spectrum of health care through the framework developed by the NQF serve as essential foundations for ensuring quality in the field.

The next step in the evolution and maturation of palliative care is the development, field testing, and implementation of outcome measures, so quality of care can be determined, compared, and continually improved. Several local and regional efforts are already in place to develop such measures, exemplified by the work of Dr. Karl Lorenz at RAND, and Dr. Laura Hanson with the support of the state of North Carolina Quality Improvement Organization.

The RAND Cancer-Quality-ASSIST (Assessing Symptoms, Side Effects and Indicators of Supportive Treatment) Project is using systematic reviews of the literature to identify evidence-based potential indicators of supportive cancer care addressing symptoms and complications of cancer, treatment-associated toxicities, and information and care planning needs of cancer patients. These potential indicators will be subjected to expert panel consideration, using an explicit group judgment process to define valid and feasible indicators for assessing health care system performance. ASSIST is building upon RAND’s previous experience in the Assessing Care of the Vulnerable Elderly (ALCOVE) project which also addressed palliative or end of life care and identified approximately 20 general quality indicators for mostly noncancer conditions. Both of these indicator sets are examples of measurable standards that could be used to implement to some degree NQFs framework.<sup>5</sup>

An example of a national project is the RAND Corporation’s effort to develop outcome measures for the preferred practices enumerated in the NQF framework document. As palliative care becomes normalized within health care systems, it can be expected that government agencies and payers at all levels will have a voice in promoting standardization of practices through orderly implementation of the NCP and NQF guidelines.

### ***Future of the NCP***

The NCP was initially developed in 2001 with the mission of the producing the clinical

*Table 3*  
**NQF Preferred Practices**

Domain 1.1: General Structure of Care	<p>Preferred Practice 1 Provide palliative and hospice care by an interdisciplinary team of skilled palliative care professionals, including, for example, physicians, nurses, social workers, pharmacists, spiritual care counselors, and others who collaborate with primary health care professional(s).</p> <p>Preferred Practice 2 Provide access to palliative and hospice care that is responsive to the patient and family 24 hours a day, seven days a week.</p>
Domain 1.1: General Structure of Care	<p>Preferred Practice 3 Provide continuing education to all health care professionals on the domains of palliative care and hospice care.</p> <p>Preferred Practice 4 Provide adequate training and clinical support to assure that professional staff are confident in their ability to provide palliative care for patients.</p>
Domain 1.1: General Structure of Care	<p>Preferred Practice 5 Hospice care and specialized palliative care professionals should be appropriately trained, credentialed, and/or certified in their area of expertise.</p>
Domain 1.2: General Processes of Care	<p>Preferred Practice 6 Formulate, utilize, and regularly review a timely care plan based on a comprehensive interdisciplinary assessment of the values, preferences, goals, and needs of the patient and family and, to the extent that existing privacy laws permit, ensure that the plan is broadly disseminated, both internally and externally, to all professionals involved in the patient's care.</p> <p>Preferred Practice 7 Ensure that on transfer between health care settings, there is timely and thorough communication of the patient's goals, preferences, values, and clinical information so that continuity of care and seamless follow-up are assured.</p>
Domain 1.2: General Processes of Care	<p>Preferred Practice 8 Health care professionals should present hospice as an option to all patients and families when death within a year would not be surprising and reintroduce the hospice option as the patient declines.</p> <p>Preferred Practice 9 Patients and caregivers should be asked by palliative and hospice care programs to assess physicians'/health care professionals' ability to discuss hospice as an option.</p>
Domain 1.2: General Processes of Care	<p>Preferred Practice 10 Enable patients to make informed decisions about their care by educating them on the process of their disease, prognosis, and the benefits and burdens of potential interventions.</p> <p>Preferred Practice 11 Provide education and support to families and unlicensed caregivers based on the patient's individualized care plan to assure safe and appropriate care for the patient.</p>
Domain 2: Physical Aspects of Care	<p>Preferred Practice 12 Measure and document pain, dyspnea, constipation, and other symptoms using available standardized scales.</p> <p>Preferred Practice 13 Assess and manage symptoms and side effects in a timely, safe, and effective manner to a level acceptable to the patient and family.</p>
Domain 3: Psychological and Psychiatric Aspects of Care	<p>Preferred Practice 14 Measure and document anxiety, depression, delirium, behavioral disturbances, and other common psychological symptoms using available standardized scales.</p> <p>Preferred Practice 15 Manage anxiety, depression, delirium, behavioral disturbances, and other common psychological symptoms in a timely, safe, and an effective manner to a level acceptable to the patient and family.</p>
Domain 3: Psychological and Psychiatric Aspects of Care	<p>Preferred Practice 16 Assess and manage psychological reactions of patients and families to address emotional and functional impairment and loss (including stress, anticipatory grief, and coping) in a regular ongoing fashion.</p> <p>Preferred Practice 17 Develop and offer a grief and bereavement care plan to provide services to patients and families prior to and for at least 13 months after the death of the patient.</p>

*(Continued)*

Table 3  
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Domain 4: Social Aspects of Care	<p>Preferred Practice 18 Conduct regular patient and family care conferences with physicians and other appropriate members of the interdisciplinary team to provide information, discuss goals of care, disease prognosis, and advanced care planning, and offer support.</p> <p>Preferred Practice 19 Develop and implement a comprehensive social care plan that addresses the social, practical, and legal needs of the patient and caregivers, including, but not limited to, relationships, communication, existing social and cultural networks, decision making, work and school settings, finances, sexuality/intimacy, caregiver availability/stress, and access to medicines and equipment.</p>
Domain 5: Spiritual, Religious, and Existential Aspects of Care	<p>Preferred Practice 20 Develop and document a plan based on assessment of religious, spiritual, and existential concerns using a structured instrument and integrate the information obtained from the assessment into the palliative care plan.</p>
Domain 5: Spiritual, Religious, and Existential Aspects of Care	<p>Preferred Practice 21 Provide information about the availability of spiritual care services and make spiritual care available either through organizational spiritual counseling or through the patient's own clergy relationships.</p>
Domain 5: Spiritual, Religious, and Existential Aspects of Care	<p>Preferred Practice 22 Specialized palliative and hospice care teams should include spiritual care professionals appropriately trained and certified in palliative care.</p> <p>Preferred Practice 23 Specialized palliative and hospice spiritual care professionals should build partnerships with community clergy and provide education and counseling related to end-of-life care.</p>
Domain 6: Cultural Aspects of Care	<p>Preferred Practice 24 Incorporate cultural assessment as a component of comprehensive palliative and hospice care assessment, including but not limited to locus of decision making, preferences regarding disclosure of information, truth telling and decision making, dietary preferences, language, family communication, desire for support measures such as palliative therapies and complementary and alternative medicine, perspectives on death, suffering and grieving, and funeral/burial rituals.</p>
Domain 6: Cultural Aspects of Care	<p>Preferred Practice 25 Provide professional interpreter services and culturally sensitive materials in the patient's and family's preferred language.</p>
Domain 7: Care of the Imminently Dying Patient	<p>Preferred Practice 26 Recognize and document the transition to the active dying phase and communicate to the patient, family, and staff the expectation of imminent death.</p> <p>Preferred Practice 27 The family is educated on a timely basis regarding signs and symptoms of imminent death in a developmentally, age, and culturally appropriate manner.</p>
Domain 7: Care of the Imminently Dying Patient	<p>Preferred Practice 28 As part of the ongoing care planning process, routinely ascertain and document patient and family wishes about the care setting for site of death and fulfill patient and family preferences when possible.</p> <p>Preferred Practice 29 Provide adequate dosage of analgesics and sedatives as appropriate to achieve patient comfort during the active dying phase and address concerns and fears about using narcotics and of analgesics hastening death.</p>
Domain 7: Care of the Imminently Dying Patient	<p>Preferred Practice 30 Treat the body post-death with respect according to the cultural and religious practices of the family and in accordance with local law.</p> <p>Preferred Practice 31 Facilitate effective grieving by implementing in a timely manner a bereavement care plan after the patient's death, when the family remains the focus of care.</p>
Domain 8: Ethical and Legal Aspects of Care	<p>Preferred Practice 32 Document the designated surrogate/decision maker in accordance with state law for every patient in primary, acute, and long-term care and in palliative and hospice care.</p> <p>Preferred Practice 33 Document the patient/surrogate preferences for goals of care, treatment options, and setting of care at first assessment and at frequent intervals as conditions change.</p>

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Table 3  
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Domain 8: Ethical and Legal Aspects of Care	Preferred Practice 34 Convert the patient treatment goals into medical orders and ensure that the information is transferable and applicable across care settings, including long-term care, emergency medical services, and hospitals, such as the Physician Orders for Life-Sustaining Treatments Program.
Domain 8: Ethical and Legal Aspects of Care	Preferred Practice 35 Make advance directives and surrogacy designations available across care settings, while protecting patient privacy and adherence to Health Insurance Portability and Accountability Act regulations, for example, by internet-based registries or electronic personal health records.
Domain 8: Ethical and Legal Aspects of Care	Preferred Practice 36 Develop health care and community collaborations to promote advance care planning and completion of advance directives for all individuals, for example, Respecting Choices, Community Conversations on Compassionate Care. Preferred Practice 37 Establish or have access to ethics committees or ethics consultation across care settings to address ethical conflicts at the end of life.
Domain 8: Ethical and Legal Aspects of Care	Preferred Practice 38 For minors with decision-making capacity, document the child's views and preferences for medical care, including assent for treatment, and give appropriate weight in decision making. Make appropriate professional staff members available to both the child and the adult decision maker for consultation and intervention when the child's wishes differ from those of the adult decision maker.

practice guidelines. When that objective was achieved, the NCP reevaluated its role, and in 2006 the participant organizations affirmed their role in disseminating the NCP guidelines and in promoting awareness and implementation of the NQF framework. Among the most important consequences of the NCP has been the illustration of the rapid and effective impact of a concerted and collaborative effort by all the major stakeholders in the palliative care field. The collective voice of the leading palliative care organizations offers the health care community and consumers a powerful and cohesive voice to advocate for quality palliative care. There are many opportunities for this coalition to continue to serve as a unified voice in advocating necessary policies for the field going forward. The NCP will continue its focus on dissemination of the NCP guidelines, now encompassing the NQF framework and preferred practices. Additionally, the NCP guidelines will

be updated to assure a current and evidence-based foundation upon which palliative care programs and professionals can develop and improve.

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