

National Consensus Project Clinical Practice Guidelines for Quality Palliative Care Guidelines, 4th Edition

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Abstract

Background: The goal of the 4th edition of the National Consensus Project Clinical Practice Guidelines for Quality Palliative Care (NCP Guidelines) is to improve access to quality palliative care for all people with serious illness regardless of setting, diagnosis, prognosis, or age.

Objective: The NCP Guidelines are intended to encourage and guide healthcare organizations and clinicians (including nonpalliative care specialists) across the care continuum to integrate palliative care principles and best practices into their routine assessment and care of all seriously ill patients and their family caregivers.

Methods: The NCP Guidelines formalize and delineate evidence-based processes and practices for the provision of safe and reliable high-quality palliative care for adults, children, and families with serious illness in all care settings.

Results: This article presents the key domains and guidelines of the 4th edition.

Keywords: access to palliative care; continuity of palliative care; culturally inclusive palliative care; inclusive of all serious illnesses; National Consensus Project; quality palliative care

Introduction

THE 4TH EDITION of the *National Consensus Project Clinical Practice Guidelines for Quality Palliative Care* (NCP) Guidelines expands upon the content in the previous edition, specifically focusing on the two key concepts. First, palliative care is inclusive of all people with serious illness, regardless of setting, diagnosis, prognosis, or age. Second, timely consideration of palliative care is the responsibility of all clinicians and disciplines caring for the seriously ill, including primary care practices, specialist care practices (e.g., oncology or neurology), hospitalists, nursing home staff, as well as palliative care specialist teams such as hospice, hospital, and community-based palliative care teams.

In addition, five key themes were added to each domain:

- The elements of a comprehensive assessment are described
- Family caregiver assessment, support, and education are referenced in numerous domains
- The essential role of care coordination, especially during care transitions, is emphasized
- Culturally inclusive care is referenced in all the domains and expanded in the cultural aspects of care domain

- Communication (within the palliative care team, with patients and families, with other clinicians, and with community resource providers) is prerequisite for delivery of quality care for the seriously ill and is emphasized throughout

Settings of Care

Since palliative care is not setting-specific, palliative care principles and practices are applicable throughout the course of a serious illness, across and between care settings, thereby improving continuity and coordination of care and, as a consequence, decreasing expenses related to duplicative or nonbeneficial interventions or waste.

While hospital-based palliative care and hospice are widely available in the United States, access to palliative care in other settings is often unavailable. Reliable access to palliative care in community-based settings is essential to the delivery of expert care and pain and symptom management, as well as psychological, practical, and social support, helping patients and families remain safely in their care setting of choice.

New community-based palliative care models are meeting the needs of those with a serious illness who are neither

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hospitalized nor hospice-eligible, through provision of care in patient homes, physician offices/clinics, cancer centers, dialysis units, assisted and long-term care facilities, and other community settings. Community-based palliative care services are delivered by clinicians in primary care and specialty care practices (such as oncologists), as well as home-based medical practices, private companies, home health agencies, hospices, and health systems.

Using the NCP Guidelines

The NCP Guidelines delineate palliative care principles that all clinicians should integrate into the care of seriously ill patients and their families. New, emerging, and established specialist palliative care teams can use the NCP Guidelines to expand services to new patient populations or care settings, form new partnerships, and improve the care provided to patients and families. Primary palliative care providers can integrate the knowledge and skills within the criteria, as well as the specific strategies outlined in the Application to Primary Palliative Care section of each domain. The NCP Guidelines can be utilized to design new palliative care programs, develop and refine educational programs, measure the effectiveness of and improve care, develop payer contracts, shape research, and prepare for healthcare accreditation.

Guidelines for Quality Palliative Care

The following are a summary of the domains and brief comments on the clinical implications of each domain.

Domain 1: Structure and processes of care

Palliative care principles and practices can be integrated into any healthcare setting, delivered by all clinicians, and supported by palliative care specialists who are part of an interdisciplinary team (IDT) with the professional qualifications, education, training, and support needed to deliver optimal patient- and family-centered care. Palliative care begins with a comprehensive assessment and emphasizes patient and family engagement, communication, care coordination, and continuity of care across healthcare settings.

Guideline 1.1: Interdisciplinary team. Since palliative care is holistic in nature, it is provided by a team of physicians, advanced practice registered nurses, physician assistants, nurses, social workers, and chaplains. The palliative care team works with other clinicians and community service providers supporting continuity of care throughout the illness trajectory and across all settings, especially during transitions of care. Depending on care setting and patient population, IDT members may be certified palliative care specialists in their discipline and/or have additional training in palliative care. Primary care and other clinicians work with interdisciplinary colleagues to integrate palliative care into routine practice.

Guideline 1.2: Comprehensive palliative care assessment. An interdisciplinary comprehensive assessment of the patient and family forms the basis for the development of an individualized patient and family palliative care plan.

Guideline 1.3: Palliative care plan. In collaboration with the patient and family, the IDT develops, implements, and updates the care plan to anticipate, prevent, and treat physical, psychological, social, and spiritual needs.

Guideline 1.4: Continuity of palliative care. The IDT has defined processes to ensure access, quality, and continuity of care, especially during transitions of care.

Guideline 1.5: Care settings. Palliative care is provided in any care setting, including private residences, assisted living facilities, rehabilitation, skilled and intermediate care facilities, acute and long-term care hospitals, clinics, hospice residences, correctional facilities, and homeless shelters.

Guideline 1.6: IDT education. Education, training, and professional development are available to the IDT.

Guideline 1.7: Coordination of care and care transitions. Care is coordinated and characterized as the right care at the right time throughout the course of an individual's disease(s) or condition. The IDT recognizes that transitions of care occur within care settings, between care settings, and between care providers. Care transitions are anticipated, planned, and coordinated to ensure that patient goals are achieved.

Guideline 1.8: Emotional support to the IDT. Providing palliative care to patients with a serious illness and their families has an emotional impact, therefore the IDT creates an environment of resilience, self-care, and mutual support.

Guideline 1.9: Continuous quality improvement. In its commitment to continuous quality improvement, the IDT develops, implements, and maintains a data-driven process focused on patient- and family-centered outcomes using established quality improvement methodologies.

Guideline 1.10: Stability, sustainability, and growth. Recognizing limitations in reimbursement for interdisciplinary palliative care, IDTs endeavor to secure funding for long-term sustainability and growth.

Clinical implications. Across patient populations and care settings from diagnosis to end of life, palliative care can prevent and relieve suffering and optimize quality of life for patients and families. Well-trained and well-supported IDTs perform comprehensive assessments and develop and implement palliative care plans in coordination with the patient, family, and other healthcare and community providers, respecting patient and family values, culture, preferences, and goals.

Domain 2: Physical aspects of care

Physical care of seriously ill patients begins with an understanding of the patient goals in the context of their physical, functional, emotional, and spiritual well-being. The assessment and care plan focus on relieving symptoms and improving or maintaining functional status and quality of life. The management of symptoms encompasses pharmacological,

nonpharmacological, interventional, behavioral, and complementary treatments. Physical care, acute and chronic symptom management across all care settings, is accomplished through communication, collaboration, and coordination between all professionals involved in the patients' care, including primary and specialty care providers.

Guideline 2.1: Global. The palliative care IDT endeavors to relieve suffering and improve quality of life, as defined by the patient and family, through the safe and timely reduction of the physical symptoms and functional impairment associated with serious illness.

Guideline 2.2: Screening and assessment. The IDT assesses physical symptoms and their impact on well-being, quality of life, and functional status.

Guideline 2.3: Treatment. Interdisciplinary care plans to address physical symptoms, maximize functional status, and enhance quality of life are developed in the context of the patient's goals of care, disease, prognosis, functional limitations, culture, and care setting. An essential component of palliative care is ongoing management of physical symptoms, anticipating changes in health status, and monitoring of potential risk factors associated with the disease and side effects due to treatment regimens.

Guideline 2.4: Ongoing care. The palliative care team provides written and verbal recommendations for monitoring and managing physical symptoms.

Clinical implications. In all care settings, palliative care seeks to improve physical comfort, quality of life, and optimal functional status. Physical concerns, including ongoing access to medications, can be exacerbated as patients transfer across settings of care. Expert symptom management focuses on physical, emotional, spiritual, religious, and cultural factors, as well as the patient's and family's goals, needs, culture, ages, and developmental status.

Domain 3: Psychological and psychiatric aspects of care

The palliative care IDT systematically addresses psychological and psychiatric aspects of care in the context of serious illness. IDTs conduct comprehensive developmentally and culturally sensitive mental status screenings of seriously ill patients. The social worker facilitates mental health assessment and treatment in all care settings, either directly, in consultation, or through referral to specialist level psychological and/or psychiatric care. The IDT communicates to the patient and family the implications of psychological and psychiatric aspects of care in establishing goals of care and developing a treatment plan, addressing family conflict, delivering grief support and resources from the point of diagnosis onward, and providing referrals for patients or family members who require additional support.

Guideline 3.1: Global. The IDT includes a social worker with the ability and skillset to assess and support mental health issues, provide emotional support, and address emotional distress and quality of life for patients and families

experiencing the expected responses to serious illness. The IDT has the training and skills to assess and support those with mental health disorders, either directly, in consultation, or through referral to specialist level psychological and/or psychiatric care.

Guideline 3.2: Screening and assessment. The IDT screens for and assesses psychological and psychiatric aspects of care based upon the best available evidence to maximize patient and family coping and quality of life.

Guideline 3.3: Treatment. The IDT manages and/or supports psychological and psychiatric aspects of patient and family care, including emotional or existential distress, related to the experience of serious illness, as well as identified mental health disorders. Psychological and psychiatric services are provided either directly, in consultation, or through referral to other providers.

Guideline 3.4: Ongoing care. The IDT provides recommendations for monitoring and managing long-term and emerging psychological responses and mental health concerns.

Clinical implications. Palliative care teams rely on social workers, psychologists, and psychiatrists to ensure that all patients and families have access to treatments that are evidence-based and provided in accordance with their values, assessed needs, and goals of care. Education related to assessment and treatment of psychological and psychiatric aspects of care, including substance use disorder, is an essential element of quality palliative care as are grief assessments and services.

Domain 4: Social aspects of care

Social determinants of health, hereafter encompassed in the term "social factors," have a strong and sometimes overriding influence on patients with a serious illness. Palliative care addresses environmental and social factors that affect patient and family functioning and quality of life. The palliative care IDT partners with the patient and family to identify and support their strengths and to address areas of need. The IDT includes a professional social worker to maximize patient functional capacity and achieve patient and family goals.

Guideline 4.1: Global. The palliative care IDT has the skills and resources to identify and address, either directly or in collaboration with other service providers, the social factors that affect patient and family quality of life and well-being.

Guideline 4.2: Screening and assessment. The IDT screens for and assesses patient and family social supports, social relationships, resources, and care environment based on the best available evidence to maximize coping and quality of life.

Guideline 4.3: Treatment. In partnership with the patient, family, and other providers, the IDT develops a care plan for social services and supports in alignment with the patient's condition, goals, social environment, culture, and

setting to maximize patient and family coping and quality of life across all care settings.

Guideline 4.4: Ongoing care. A palliative care plan addresses the ongoing social aspects of patient and family care, in alignment with their goals and provides recommendations to all clinicians involved in ongoing care.

Clinical implications. The palliative care IDT assesses the social and environmental strengths and vulnerabilities of patients and families to determine their ability to cope with serious illness and maximize quality of life. The IDT plans for, arranges, and coordinates services and supports to address patient and family social and functional goals that enable the patient to remain in the setting of their choice, to the extent possible. The IDT incorporates specialists in social aspects of care specific to the cultural and developmental needs of each patient.

Domain 5: Spiritual, religious, and existential aspects of care

Spirituality is recognized as a fundamental aspect of compassionate, patient- and family-centered palliative care. It is a dynamic and intrinsic aspect of humanity, through which individuals seek meaning, purpose, and transcendence and experience relationship to self, family, others, community, society, and the significant or sacred. Spirituality is expressed through beliefs, values, traditions, and practices. The palliative care IDT serves each patient and family in a manner that respects their spiritual beliefs and practices and is also respectful when patients and families decline to discuss their beliefs or accept spiritual support.

Guideline 5.1: Global. Patient and family spiritual beliefs and practices are assessed and respected. Palliative care professionals acknowledge their own spirituality as part of their professional role and are provided with education and support to address each patient's and family's spirituality.

Guideline 5.2: Screening and assessment. The spiritual assessment process has three distinct components—spiritual screening, spiritual history, and a full spiritual assessment. The spiritual screening is conducted with every patient and family to identify spiritual needs and/or distress. The history and assessment identify the spiritual background, preferences, and related beliefs, values, rituals, and practices of the patient and family. Symptoms, such as spiritual distress and spiritual strengths and resources, are identified and documented.

Guideline 5.3: Treatment. The IDT addresses the spiritual needs of the patient and family.

Guideline 5.4: Ongoing care. Patient and family spiritual care needs can change as the goals of care change or patients move across settings of care.

Clinical implications. Spiritual care is an essential component of quality palliative care. Spiritual care services, including screening, history, and assessment, are performed on admission and regularly thereafter. Interventions using

professional standards of practice are part of the basic provision of quality care available to all palliative patients.

Domain 6: Cultural aspects of care

Assessing and respecting values, beliefs, and traditions related to health, illness, family caregiver roles, and decision-making are the first step in providing culturally sensitive palliative care. Palliative care IDT members continually expand awareness of their own biases and perceptions about race, ethnicity, gender identity and gender expression, sexual orientation, immigration and refugee status, social class, religion, spirituality, physical appearance, and abilities. Information gathered through a comprehensive assessment is used to develop a care plan that incorporates culturally sensitive resources and strategies to meet the needs of patients and family members. Respectful acknowledgment of and culturally sensitive support for patient and family grieving practices are provided.

Guideline 6.1: Global. The IDT delivers care that respects patient and family cultural beliefs, values, traditional practices, language, and communication preferences and builds upon the unique strengths of the patient and family. Each member of the IDT works to increase awareness of their own biases and seeks opportunities to learn about the provision of culturally sensitive care. The care team ensures that its environment, policies, procedures, and practices are culturally respectful.

Guideline 6.2: Communication and language. The IDT ensures that patient and family preferred language and style of communication are supported and facilitated in all interactions.

Guideline 6.3: Screening and assessment. The IDT uses evidence-based practices when screening and assessing patient and family cultural preferences regarding healthcare practices, customs, beliefs and values, level of health literacy, and preferred language.

Guideline 6.4: Treatment. A culturally sensitive plan of care is developed and discussed with the patient and/or family. This plan reflects the degree to which patients and families wish to be included as partners in decision-making regarding their care. When hosting meetings to discuss and develop the plan, the program ensures that patient and family linguistic needs are met.

Clinical implications. For patients and family members to receive culturally sensitive care, it is incumbent on professionals to continually explore their own biases, work to avoid judgment, and seek frequent training to enhance and strengthen their cultural assessment, treatment, and communication skills.

Domain 7: Care of the patient nearing the end of life

This domain highlights the care provided to the patient and their family near the end of life, with a particular emphasis on the days leading up to and just after the death of the patient. The meticulous and comprehensive assessment and

management of pain and other physical symptoms, as well as social, spiritual, psychological, and cultural aspects of care, are critically important as the patient nears death. It is essential that the IDT ensures reliable access and attention in the days before death and provides developmentally appropriate education to the patient, family, and/or other caregivers about what to expect near death, as well as immediately following the patient's death.

The interdisciplinary model of hospice care is recognized conceptually and philosophically as the best care for patients nearing the end of life. Discussion regarding hospice as an option for support should be introduced early so that patients and families can understand eligibility and the benefits and limitations of accessing this care model. Early access to hospice support should be facilitated whenever possible to optimize care outcomes for the patient and the family. Palliative care teams, hospice providers, and other healthcare organizations must work together to find innovative, sustainable supportive care solutions for all patients and families in their final months of life.

Guideline 7.1: Interdisciplinary team. The IDT includes professionals with training in end-of-life care, including assessment and management of symptoms, communicating with patients and families about signs and symptoms of approaching death, transitions of care, and grief and bereavement. The IDT has established structures and processes to ensure appropriate care for patients and families when the end of life is imminent.

Guideline 7.2: Screening and assessment. The IDT assesses physical, psychological, social, and spiritual needs as well as patient and family preferences for setting of care, treatment decisions, and wishes during and immediately following death. Discussions with the family focus on honoring patient wishes and attending to family fears and concerns about the end of life. The IDT prepares and supports family caregivers throughout the dying process, taking into account the spiritual and cultural background and preferences of the patient and family.

Guideline 7.3: Treatment before death. In collaboration with the patient and family and other clinicians, the IDT develops, implements, and updates as needed a care plan to anticipate, prevent, and treat physical, psychological, social, and spiritual symptoms. The care plan addresses the focus on end-of-life care and treatments to meet the physical, emotional, social, and spiritual needs of patients and families. All treatments are provided in a culturally and developmentally appropriate manner.

Guideline 7.4: Treatment during the dying process and immediately after the death. During the dying process, patient and family needs are respected and supported. Postdeath care is delivered in a manner that honors patient and family cultural and spiritual beliefs, values, and practices.

Guideline 7.5: Bereavement. Bereavement support is available to the family and care team, either directly or through referral. The IDT identifies or provides resources, including grief counseling, spiritual support, or peer support,

specific to the assessed needs. Prepared in advance of the patient's death, the bereavement care plan is activated after the death of the patient and addresses immediate and longer-term needs.

Clinical implications. While the IDT may follow a patient in palliative care from diagnosis to end of life, additional clinical skills help to identify signs and symptoms of approaching death. Discussions about, and referral to, hospice are offered as early as possible. The IDT must assess fears, address concerns, provide caregiver training, and support the family through the dying process and postdeath. It is essential that the IDT attends to patient and family cultural and spiritual beliefs, values, and practices to promote a peaceful, dignified, and respectful death, in all settings of care.

Domain 8: Ethical and legal aspects of care

The palliative care IDT applies ethical principles to the care of patients with serious illness, including honoring patient preferences as well as decisions made by legal proxies or surrogate decision makers. It is important to note that in all cases, surrogates' obligations are to represent the patient's preferences or best interests. Familiarity with local and state laws is needed relating to advance care planning, decisions regarding life-sustaining treatments, and evolving treatments with legal ramifications (e.g., medical marijuana), especially when caring for vulnerable populations, such as minors, prisoners, or those with developmental disability or psychiatric illness.

Guideline 8.1: Global. The core ethical principles of autonomy, substituted judgment, beneficence, justice, and nonmaleficence underpin the provision of palliative care.

Guideline 8.2: Legal considerations. The provision of palliative care occurs in accordance with federal, state, and local regulations and laws as well as current accepted standards of care and professional practice.

Guideline 8.3: Screening and assessment. The patient's preferences and goals for medical care are elicited using core ethical principles and documented.

Guideline 8.4: Treatment and ongoing decision making. Within the limits of applicable state and federal laws, current accepted standards of medical care, and professional standards of practice, person-centered goals form the basis for the plan of care and decisions related to providing, forgoing, and discontinuing treatments.

Clinical implications. Ethical and legal principles are inherent to the provision of palliative care to patients with serious illness, including principles of self-determination, beneficence, nonmaleficence, and justice. Clinicians understand ethical principles underlying healthcare delivery in the context of their own professional practice setting and discipline, as well as the laws and statutes governing healthcare. In all contexts, the IDT provides attention to moral agency and emphasis on collaborative practice. The IDT is mindful of its own values and beliefs when facilitating informed decision-making and participating in ethical dilemma resolution and recognizes the

importance of maintaining professional boundaries across all settings and contexts, regardless of patient age.

Conclusion

The NCP Guidelines, 4th edition, will advance the field of palliative care. The complete NCP Guidelines, detailed criteria, implications, bibliography, and practice examples can be found at www.nationalcoalitionhpc.org/ncp. To view the systematic review of evidence supporting the guidelines conducted by The Rand Corporation, go to: www.crd.york.ac.uk/PROSPERO/display_record.php?ID=CRD42018100065.

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