



Quality Focus:

Guidelines for Quality Palliative Care

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The increasing number of patients with chronic, debilitating, life-threatening illness has led providers to consider issues related to palliative and hospice care. Providing quality end-of-life care requires a patient-centered process that involves coordination within a multidisciplinary team.

The National Consensus Project for Quality Palliative Care, representing five major U.S. palliative care organizations, has established guidelines to promote consistent quality care within the structure of ongoing services. These guidelines should be considered to assist in assessment, information sharing, decision-making, planning and care delivery for patients facing end-of-life needs.

The structure should be interdisciplinary and include both the patient and the family. The team should include appropriately trained individuals and supervised volunteers. Support for education and training should be available for the provider team members. The physical environment in which care is provided should meet the preferences, needs and circumstances of the patient and family to the best extent possible. Clinical aspects of care involve pain control and comfort measures as well as other symptoms and side effects that need skillful application. Barriers to effective pain management and sedation (i.e., fear of side effects, addiction, respiratory depression) should be recognized and addressed. The psychological and psychiatric aspects as well as the social needs of the patient need constant assessment.

Also important are cultural, spiritual and religious concerns, including a grief and bereavement program that is available to patient and family. Signs of impending or imminent death should be noted and communicated. The patient's goals, preferences and choices should be respected within the limits of applicable state and federal laws.

The program should address the complex ethical issues arising in the care of persons with life-threatening, debilitating illness. Providers should be knowledgeable about legal and regulatory aspects of palliative care including wills and guardianship agreements. They should also be aware of the dilemmas related to specific interventions such as withholding or withdrawing nutrition or hydration. Self-determination choices and informed consent should be recognized and defined. All those involved in the care and decision-making process should understand the DNR/DNI status.

Palliative care is a growing practice specialty and providers need fundamental training across many treatment settings. The service should be easily accessible 24/7. Respite care should be encouraged to help support family members and those providing the care at home. The process should be constantly reassessed to ensure that appropriate care is being given.

Providers may often face family members and patients who have developed unrealistic goals due to misinformation perpetuated by multiple outside sources. Hopefully, guidelines will foster patient-centered quality care at the end of life and not futile efforts with inappropriate or unnecessary care.

The following three tables were taken from:

1. "Guidelines for Delivering Quality Palliative Care," *American Family Physician*, Vol. 73, No. 6, March 15, 2006
2. NCPQPC "Clinical Practice Guidelines for Quality Palliative Care"
3. <http://www.nationalconsensusproject.org>

TABLE 1. Models of Palliative Care

Model	Associated facilities
Combined consultative service team and inpatient unit	Hospital, nursing home
Combined hospice program and palliative care program	Hospital, nursing home, freestanding hospice inpatient facilities
Consultation service team (physician and nurse)	Usually in a hospital, office, nursing home, or home; may include social work evaluations
Dedicated inpatient unit	Acute and rehabilitation hospital, nursing home; sometimes combined with a freestanding inpatient hospice
Hospice-based consultation in outpatient settings	Outpatient settings
Hospice-based palliative care in the home	Home
Outpatient palliative care practice or clinic	Hospital or private practice

TABLE 2. Core Outcomes of Palliative Care

Care should be coordinated across settings through regular, high-quality communication during transitions or when needs change and through effective case management.
Control of pain and symptoms, psychosocial distress, spiritual issues, and practical need should be addressed with the patient and family throughout the care continuum.
Patients and families should be prepared for the process of dying and for death, if anticipated, with exploration of hospice options, enhancement of personal growth opportunities, and availability of bereavement support.
Patients and families should receive ongoing information that enables their full understanding of the condition and options; their values and goals should be elicited; the pros and cons of treatment should be reassessed on a regular basis; and decisions of care should be sensitive to changes in patients' conditions.

TABLE 3. Areas of Palliative Care Requiring Regular Assessment and Documentation

Area	Examples
Physical	Pain; nonpainful symptoms (e.g., shortness of breath, nausea, fatigue, weakness, anorexia, insomnia, anxiety, depression, confusion, constipation); treatment side effects; functional capacities; treatment efficacy and alternatives (and patient and family preferences)
Psychological	Understanding of the illness and its consequences; care giving needs or capacity; stress; grief and bereavement risks for the patient and family (i.e., depression and comorbid complications); coping strategies
Social	Family structure and geographic location; cultural concerns and needs; finances; sexuality; living arrangements; caregiver availability; access to transportation; access to prescription and over-the-counter medicines
Spiritual	Spiritual background, beliefs, and practices of the patient and family; hopes and fears; life completion tasks; wishes regarding care setting for death