Further impetus for expansion of palliative care services is the strong correlation between patient/family care preferences and the services provided by palliative care specialists. Studies show that patients' top priorities are to be free of physical and psychological distress; to have some control over decisions about their health care; to avoid death-prolonging treatments; and to improve relationships with and reduce burden on their families. (8) The evidence base of the hospice experience for patients/families during the last few months of a terminal illness, as well as more recent palliative care outcome studies, demonstrate the ability of palliative care to help patients achieve these goals throughout the trajectory of a progressive or life-threatening illness. (22) Other studies have demonstrated financial benefits associated with palliative care programs, including reduction in hospital length of stay, costs and utilization, (23) and increased numbers of referrals to and length of stay in hospice programs. (24)

The need for palliative care in the United States can be met through ongoing health professional education in palliative care principles and practice; increasing access to palliative care specialists in hospital, nursing home and home care settings; promoting timely access to hospice services to all eligible patients; creatively integrating hospice and palliative care programs across treatment settings; and defining appropriate accountability and performance measures for palliative care services.

Palliative Care Across the Continuum

The growing need for and interest in palliative care underscores the importance of practice guidelines aimed at promoting palliative care clinical services of a high and consistent quality across all relevant care settings in the United States. Most people receive health care in multiple clinical settings: physicians' offices, hospitals, school-based clinics, nursing homes, emergency facilities and at home. It is well established that communication among these various care settings is extremely difficult, resulting in discontinuities of care. Continuity of care is especially important for patients and families facing life-threatening illness or injury. Toward this end, a core value of palliative care is the promotion and facilitation of continuity of care to avoid needless suffering and errors, eliminate patient and family perceptions of abandonment, and ensure that choices and preferences are respected. (13, 15)

Almost all persons with serious illness spend at least some time in a hospital, usually on multiple occasions, in the course of the disease or condition. More than 50 percent of adult and 85 percent of pediatric deaths occur in hospitals. Similarly, almost half the population age 65 or older will spend some time in a nursing home prior to death, more than half of persons over age 85 die in a nursing home, and 43 percent of persons over age 65 reside in a long-term care facility at some time before they die. (26) Data from numerous studies demonstrate high degrees of symptom distress across all age groups in hospitalized and nursing home patients; high use of burdensome nonbeneficial technologies among the seriously ill; (27) caregiver burden on families; (21) and problems with communication between these patients, their families and their treating physicians about the goals of care and the medical decisions that should follow. (13)

The Urban Institute reports,

"The nation is about to experience a great demographic shock. Between 2010 and 2030 the over-65 population will rise over 70 percent, while under current law the population paying payroll taxes will rise less than 4 percent."(25) This demographic change, when aligned with progressively higher health care costs, diminishing labor and financial resources, insecurity of federal entitlements and longer life expectancies creates a dramatic projection of future health care needs. Further, the number of children living with life-limiting conditions with significant disability and morbidity continues to increase. (18) These factors help to illustrate the need for more effective application and coordination of chronic disease management services, including the integration of palliative care, in order to more effectively meet the needs of the growing number of persons living with life-threatening and debilitating illnesses.

In addition to serving as a principal location of care, hospitals are the primary training site for the nation's future health care professionals. As a result, hospitals have become a major locus of current efforts to improve access to palliative care. Providers must learn how to respond competently to the various forms of human suffering, know how to work with the medical system on behalf of patients and families, and to regard care of the dying, as well as the care of the chronically and seriously ill, as a core clinical responsibility. They must be taught and mentored at their point of entry into health care and in the environment—the hospital setting—where the majority of people will spend some time during a serious illness. Students of medicine and nursing are acculturated during their training to value what is taught and practiced by their seniors. Palliative care must be taught during clinical rotations in the hospital, in order for it to be viewed as an essential competency for a health professional.

Experiences in nonhospital community settings, including hospice, are also necessary to train future practitioners in both the primary and specialist-level skills required to ensure quality palliative care across all health care settings. As mandated by both the Liaison Council on Medical Education (undergraduate medical education) and the Accreditation Council on Graduate Medical Education (residency and fellowship training), this requires formal educational experiences both within and outside the hospital environment in order to fully understand the importance of continuity of care and the challenges of delivering it. Furthermore, the essential skills of learning to access and utilize community resources, and how to establish practice patterns that will promote palliative care in all settings, can only be gained through educational experiences in the range of settings where patients receive care. (28)

While the practice guidelines for palliative care clinical programs contained in this document are applicable in institutional settings for both pediatric and adult patient populations, focused efforts are required to improve access to quality palliative care in nursing homes, where perceived and actual regulatory barriers, limited resources and staff turnover often make the provision of expert palliative care services difficult. Additional education and training of nursing home professionals and all direct-care staff in the principles and practice of palliative care is a priority of long-term care professional organizations, and many facilities are developing palliative care capabilities on-site or through contractual relationships with palliative care clinicians. Promotion of contractual relationships between nursing homes and hospices is also a prevalent and growing model of palliative care delivery in the nursing home setting. Compared to nursing homes without hospice relationships, homes with hospice relationships show significant reductions in hospitalizations, hospital lengths of stay, restraint use, use of injection analgesics, and insertion of intravenous lines and feeding tubes, as well as a higher likelihood of detection and treatment of pain. (29) Consequently, a nursing home's ability to provide the types of palliative services identified in this document may be achieved through development of on-site capabilities in the delivery of quality palliative care; through seeking one or more contractual relationships with local hospices or palliative care experts; and, as some long-term care facilities have demonstrated, through development of palliative care consultation services in addition to hospice contracts. (30)

The Need for Consensus

Professional consensus on what constitutes high-quality palliative care is prerequisite to the effective delivery of such services across the continuum of care. This consensus process provides credible common ground to begin systematic improvements in palliative care delivery. In addition, the consensus process fosters the development of a broad-based and enduring palliative care constituency through the dissemination of these guidelines throughout the many sectors of the U.S. health care system.

Purpose of the Clinical Practice Guidelines for Quality Palliative Care

The mission of the National Consensus Project for Quality Palliative Care is to create a set of clinical practice guidelines to improve the quality of palliative care in the United States. Specifically, these Clinical Practice Guidelines for Quality Palliative Care aim to promote quality and reduce variation in new and existing programs, develop and encourage continuity of care across settings, and facilitate collaborative partnerships among palliative care programs, community hospices and a wide range of other health care delivery settings.

While the focus of this document is on the specialist component of palliative care (programs and professionals whose work is primarily focused on palliative care), most palliative care needs to be delivered in primary treatment settings in the course of routine care. This requires guidance for health care professionals who lack specialist training in palliative care. Thus, these guidelines are intended to serve as a comprehensive description of what constitutes a high-quality palliative care clinical service, as well as a resource for practitioners addressing the palliative care needs of patients and families in primary treatment settings.

In the United States, practice standards for palliative care during the last phase of life have developed over the last 20 years through hospice professional organizations and regulatory bodies. These standards and precepts, along with published palliative care service guidelines from Australia, New Zealand and Canada, served as the basis for the development of these clinical practice guidelines. (31)

The success of this project will be determined by the degree to which the Clinical Practice Guidelines for Quality Palliative Care are used to: 1) foster the integration of the principles, philosophy and practices of palliative care across care settings; 2) stimulate and guide the development and evaluation of new and existing services within and across care settings; 3) ensure that palliative care services deliver care of consistent and measurably high quality; 4) promote formal recognition of specialty status for certification initiatives in palliative care; and 5) support the expansion of efforts by hospices and other palliative care programs to coordinate care services across the continuum.

The purposes of these Clinical Practice Guidelines for Quality Palliative Care are to:

1. Facilitate the development and continuing improvement of clinical palliative care programs providing care to patients and families with life-threatening or debilitating illness.
2. Establish uniformly accepted definitions of the essential elements in palliative care that promote quality, consistency and reliability of these services.
3. Establish national goals for access to quality palliative care.
4. Foster performance measurement and quality improvement initiatives in palliative care services.
5. Foster continuity of palliative care across settings (home, residential care, hospital, hospice).

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NOTE: An easy reference to the various sections of the NHPCO Standards of Practice for Hospice Programs (2000) is provided in brackets at the end of each domain.

NHPCO Standards: {ARE 3, 3.1-3.3, 3.5, 3.6, 8, 14, 14.1, 14.2; CCS 3.1-3.4, 6, 10, 10.1-10.3, 11, 11.1, 11.3, 13, 13.1, 13.2, 14, 14.1, 14.2; HIF CCS 3; HIF SIC 1,1.1-1.7, 5; HRCF SIC 1, 1.1-1.9, 2, 2.1-2.6, 3, 3.1, 5, 7, 7.1-7.4; HR 1, 1.3, 4, 4.1, 4.2, 4.4, 7.2; IDT 1.1, 4.1, 5.1; PI 1.1, 2, 2.1-2.3, 3.2, 4, 4.1, 4.3, 4.4, 5.2, 5.3, 6, 6.1,6.2}[1]

[1] References from sections of the National Hospice and Palliative Care Organization Standards of Practice for Hospice Programs (2002) are cited in brackets, using their abbreviations as follows:

ARE	Access, Rights, Ethics
BCS	Bereavement Care and Services
CC	Coordination and Continuity of Care
CCS	Clinical Care and Services
HR	Human Resources
IDT	Interdisciplinary Team
LG	Leadership and Governance
MI	Management of Information
PI	Performance Improvement and Outcomes Measurement
SIC	Safety and Infection Control
HIF	Hospice Inpatient Facility
NF	Nursing Facility Hospice Care
HRCF	Hospice Residential Care Facility

Clinical Practice Guidelines for Quality Palliative Care

Baseline Assumptions

The following assumptions are fundamental to the development of the Clinical Practice Guidelines for Quality Palliative Care:

- **Goal guidelines:** These palliative care guidelines represent goals that palliative care services should strive to attain, as opposed to minimal or lowest acceptable practices.
- **Health care quality standards:** These palliative care guidelines assume that palliative care services will follow established practice standards and requirements for health care quality such as safety, effective leadership, medical record keeping and error reduction.
- **Codes of ethics:** These guidelines assume adherence to established professional and organizational codes of ethics.
- **Ongoing revision:** Palliative care guidelines will evolve as professional practice, the evidence base and the health care system change over time. These guidelines were written assuming an ongoing process of evidence-based evaluation and revision. (32)
- **Peer-defined guidelines:** These clinical practice guidelines were developed through a consensus process including a broad range of palliative care professionals; they are not linked to regulatory or reimbursement criteria and are not mandatory. However, they are written with the intent that they will be used as guidelines to promote the development of highest-quality clinical palliative care services across the health care continuum.
- **Specialty care:** When this document refers to specialty-level palliative care services it assumes provision of services by palliative care professionals within an interdisciplinary team whose work reflects substantial involvement in the care of patients with life-threatening or debilitating chronic illnesses, and their families. Palliative care qualifications are determined by organizations granting professional credentials and programmatic accreditation.
- **Continuing professional education:** These guidelines assume ongoing professional education for all palliative care professionals in the knowledge, attitudes and skills required to deliver quality palliative care across the domains established in this document.
- **Applicability of guidelines:** These guidelines should promote integration and application of the principles, philosophy and practices of palliative care across the continuum of care by both professional and certified caregivers in these settings.

Clinical Practice Guidelines for Quality Palliative Care

Excellence in specialist-level palliative care requires expertise in the clinical management of problems in multiple domains, supported by a programmatic infrastructure that furthers the goals of care and supports practitioners. Eight domains were identified as the framework for these guidelines: Structure and Processes; Physical Aspects of Care; Psychological and Psychiatric Aspects of Care; Social Aspects of Care; Spiritual, Religious and Existential Aspects of Care; Cultural Aspects of Care; Care of the Imminently Dying Patient; and Ethical and Legal Aspects of Care. These domains were drawn from the work of the previously established Australian, New Zealand, Canadian, Children's Hospice International, and NHPCO standards efforts. (31)

The guidelines rest on fundamental processes that cross all domains and encompass assessment, information sharing, decision-making, care planning and care delivery. Each domain is followed by specific clinical practice guidelines regarding professional behavior and service delivery. These are followed by justifications, supporting and clarifying statements, and suggested criteria for assessing whether or not the identified expectation has been met. References to the literature supporting these recommendations are included in the guidelines.

Domains of Quality Palliative Care

1. **Structure and Processes of Care**
2. **Physical Aspects of Care**
3. **Psychological and Psychiatric Aspects of Care**
4. **Social Aspects of Care**
5. **Spiritual, Religious and Existential Aspects of Care**
6. **Cultural Aspects of Care**
7. **Care of the Imminently Dying Patient**
8. **Ethical and Legal Aspects of Care**

Domain 1: Structure and Processes of Care

Guideline 1.1 The plan of care is based on a comprehensive interdisciplinary assessment of the patient and family. (10, 11)

Criteria:

- Assessment and its documentation are interdisciplinary and coordinated.
- Initial and subsequent assessments are carried out through patient and family interview, review of medical records, discussion with other providers, physical examination and assessment, and relevant laboratory and/or diagnostic tests or procedures. (33)
- Assessment includes documentation of disease status, including diagnoses and prognosis; comorbid medical and psychiatric disorders; physical and psychological symptoms; functional status; social, cultural, spiritual and advance care planning concerns and preferences, including appropriateness of referral to hospice. (34) Assessment of children must be conducted with consideration of age and stage of neurocognitive development. (35)
- Patient and family expectations, goals for care and for living, (8) understanding of the disease and prognosis, (13) as well as preferences for the type (8) and site of care (20, 26) are assessed and documented.
- The assessment is reviewed on a regular basis. (36)

Guideline 1.2 The care plan is based on the identified and expressed values, goals and needs of patient and family (8)**, and is developed with professional guidance and support for decision-making.** (9)

Criteria:

- The care plan is based upon an ongoing assessment, determined by goals set with patient and family, and with consideration of the changing benefit/burden assessment at critical decision points during the course of illness. (8)
- The care plan is developed through the input of patient, family, caregivers, involved health care providers, and the palliative care team with the additional input, when indicated, of other specialists (37) and caregivers, such as school professionals, clergy, friends, etc. (38)
- Care plan changes are based on the evolving needs and preferences of the patient and family over time, and recognize the complex, competing and shifting priorities in goals of care. (36)
- The interdisciplinary team coordinates and shares the information, provides support for decision-making, develops and carries out the care plan, and communicates the palliative care plan to patient and family, to all involved health professionals and to the responsible providers when patients transfer to different care settings. (13, 15)
- Treatment and care setting alternatives are clearly documented and communicated, and permit the patient and family to make informed choices. (8, 13)
- Treatment decisions are based on goals of care, assessment of risk and benefit, best evidence and patient/family preferences. Re-evaluation of treatment efficacy and patient-family preferences is documented. (36, 39)
- The evolving care plan must be clearly documented over time. (39)

Guideline 1.3 An interdisciplinary team provides services to the patient and family, consistent with the care plan.

Criteria:

- Specialist-level palliative care is delivered by an interdisciplinary team. (11)
- The team includes palliative care professionals with the appropriate patient population-specific education, credentialing and experience, and ability to meet the physical, psychological, social and spiritual needs of both patient and family. (14) Of particular importance is hiring physicians, nurses and social workers appropriately trained and ultimately certified in hospice and palliative care.
- The interdisciplinary palliative care team involved in the care of children, either as patients or as the children of adult patients, has expertise in the delivery of services for such children. (35)
- The patient and family have access to palliative care expertise and staff 24 hours per day, seven days per week. (40)
- Respite services are available for the families and caregivers of children or adults with life-threatening illnesses. (41)
- The interdisciplinary team communicates regularly (at least weekly, more often as required by the clinical situation) to plan, review and evaluate the care plan, with input from both patient and family. (42)
- The team meets regularly to discuss provision of quality care, including staffing, policies and clinical practices. (42)
- Team leadership has appropriate training, qualifications and experience. (43)
- Policies for prioritizing and responding to referrals in a timely manner are documented. (44)

Guideline 1.4 The interdisciplinary team may include appropriately trained and supervised volunteers. (45)

Criteria:

- If volunteers participate, policies and procedures are in place to ensure the necessary education of volunteers, and to guide recruitment, screening, training, work practices, support, supervision and performance evaluation, and to clarify the responsibilities of the program to its volunteers.
- Volunteers are screened, educated, coordinated and supervised by an appropriately educated and experienced professional team member.

Guideline 1.5 Support for education and training is available to the interdisciplinary team.

Criteria:

- Educational resources and continuing professional education focused on the domains of palliative care contained in this document are regularly provided to staff, and participation is documented. (46)

Guideline 1.6 The palliative care program is committed to quality improvement in clinical and management practices. (17)

Criteria:

- The palliative care program must be committed to the pursuit of excellence and the highest quality of care and support for all patients and their families. Determining quality requires regular and systematic measurement, analysis, review, evaluation, goal setting, and revision of the processes and outcomes of care provided by the program.
- Quality care must incorporate attention at all times to:
  - Safety, and the systems of care that reduce error.
  - Timeliness, care delivered to the right patient at the right time.
  - Patient-centered care, based on the goals and preferences of the patient and the family.
  - Beneficial and/or effective care, demonstrably influencing important patient outcomes or processes of care linked to desirable outcomes.
  - Equity, care that is available to all in need and who could benefit.
  - Efficiency, care designed to meet the actual needs of the patient so that it does not waste resources.
- The palliative care program establishes quality improvement policies and procedures.
- Quality improvement activities are routine, regular, reported and are shown to influence clinical practice.
- The clinical practices of palliative care programs reflect the integration and dissemination of research and evidence of quality improvement.
- Quality improvement activities for clinical services are collaborative, interdisciplinary, and focused on meeting the identified needs of patients and their families.
- Patients, families, health professionals and the community may provide input for evaluation of the program.

Guideline 1.7 The palliative care program recognizes the emotional impact on the palliative care team of providing care to patients with life-threatening illnesses and their families. (47)

Criteria:

- Emotional support is available to staff and volunteers as appropriate.
- Policies guide the support of staff and volunteers, including regular meetings for review and discussion of the impact and processes of providing palliative care.

Guideline 1.8 Palliative care programs should have a relationship with one or more hospices and other community resources in order to ensure continuity of the highest-quality palliative care across the illness trajectory. (38)

Criteria:

- Palliative care programs must support and promote continuity of care across settings and throughout the trajectory of illness.
- As appropriate, patients and families are routinely informed about and offered referral to hospice and other community-based health care resources.
- Referring physicians and health care providers are routinely informed about the availability and benefits of hospice and other community resources for care for their patients and families as appropriate and indicated.
- Policies for formal written and verbal communication about all domains in the plan of care are established between the palliative care program, hospice programs, and other major community providers involved in the patients' care. Policies enable timely and effective sharing of information among teams while safeguarding privacy.
- Where possible, hospice and palliative care program staff routinely participate in each other's team meetings to promote regular professional communication, collaboration and an integrated plan of care on behalf of patients and families.
- Palliative and hospice care programs, as well as other major community providers, routinely seek opportunities to collaborate and work in partnership to promote increased access to quality palliative care across the continuum.

Guideline 1.9 The physical environment in which care is provided should meet the preferences, needs and circumstances of the patient and family to the extent possible.

Criteria:

- When feasible, care is provided in the setting preferred by the patient and their family. (19, 20)
- When care is provided away from the patient's home, the care setting addresses safety and, as appropriate and feasible, flexible or open visiting hours, space for families to visit, rest, eat or prepare meals, and meet with the palliative care team and other professionals, as well as privacy and other needs identified by the family. (48) The setting should address the unique care needs of children as patients, family members or visitors. (35)

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NOTE: An easy reference to the various sections of the NHPCO Standards of Practice for Hospice Programs (2000) is provided in brackets at the end of each domain.

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[1] References from sections of the National Hospice and Palliative Care Organization Standards of Practice for Hospice Programs (2002) are cited in brackets, using their abbreviations as follows:

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CCS	Clinical Care and Services	HIF	Hospice Inpatient Facility
HR	Human Resources	NF	Nursing Facility Hospice Care
IDT	Interdisciplinary Team	HRCF	Hospice Residential Care Facility
LG	Leadership and Governance		

Domain 2: Physical Aspects of Care

Guideline 2.1 Pain, other symptoms and side effects are managed based upon the best available evidence, which is skillfully and systematically applied. (32)

Criteria:

- The interdisciplinary team includes professionals with specialist-level skill in symptom control (11, 14).
- Regular, ongoing assessment of pain, nonpain symptoms (including but not limited to shortness of breath, nausea, fatigue and weakness, anorexia, insomnia, anxiety, depression, confusion and constipation), treatment side effects and functional capacities are documented. (49-79) Validated instruments, where available, should be used. (80) Symptom assessment in children and cognitively impaired patients should be performed with appropriate tools. (35)
- The outcome of pain and symptom management is the safe and timely reduction of pain and symptom levels, for as long as the symptom persists, to a level that is acceptable to the patient.
- Response to symptom distress is prompt and tracked, through documentation in the medical record. (39, 51)
- Barriers to effective pain management should be recognized and addressed, including inappropriate fears of the risks of side effects, addiction, respiratory depression and hastening of death in association with opioid analgesics. (49-51)
- A risk management plan should be implemented when controlled substances are prescribed for long-term symptom management.
- Patient understanding of disease and its consequences, symptoms, side effects of treatments, functional impairment and potentially useful treatments is assessed. The capacity of the patient to secure and accept needed care and to cope with the illness and its consequences is assessed. (13) (See Domain 3: Psychological and Domain 8: Ethics).
- Family understanding of the disease and its consequences, symptoms, side effects, functional impairment and treatments is assessed. The capacity of the family to secure and provide needed care and to cope with the illness and its consequences is assessed. (13, 21)
- Treatment of distressing symptoms and side effects incorporates pharmacological, nonpharmacological and complementary/supportive therapies. (78, 79) Approach to the relief of suffering is comprehensive, addressing physical, psychological, social and spiritual aspects. (10) (See especially Domain 3: Psychological and Domain 4: Social Support).
- Referrals to health care professionals with specialized skills in symptom management are made available when appropriate (e.g., radiation therapists, anesthesia pain management specialists, orthopedists, physical and occupational therapists, child life specialists). (37)
- Family is educated and supported to provide safe and appropriate comfort measures to the patient. Family is provided with backup resources for response to urgent needs. (See Domain 3: Psychological and Domain 4: Social Support).
- A process for quality improvement and review of physical and functional assessment and effectiveness of treatment is documented and leads to change in clinical practice. (17)

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NHPCO Standards{IDT 1.1; HR 4, 4.1, 4.2, 4.4; CCS 1, 1.2, 1.3, 2, 2.1, 2.5, 3, 3.1, 3.2, 3.3, 5.4, 6, 10, 11, 13, 13.1, 13.2, 14, 14.1, 14.2; IDT 4.1, 5.1, 6, 11.2, 12, 12.1, 12.2, 12.3, 12.4, 13.3; MI 3.3; PI 4, 4.1, 4.3, 4.4}[1]

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ARE Access, Rights, Ethics
BCS Bereavement Care and Services
CC Coordination and Continuity of Care
CCS Clinical Care and Services
HR Human Resources
IDT Interdisciplinary Team
LG Leadership and Governance
MI Management of Information
PI Performance Improvement and Outcomes Measurement
SIC Safety and Infection Control
HIF Hospice Inpatient Facility
NF Nursing Facility Hospice Care
HRCF Hospice Residential Care Facility

Domain 3: Psychological and Psychiatric Aspects of Care

Guideline 3.1 Psychological and psychiatric issues are assessed and managed based upon the best available evidence, which is skillfully and systematically applied. (32, 81)

Criteria:

- The interdisciplinary team includes professionals with patient-specific skill and training in the psychological consequences and psychiatric comorbidities of serious illness for both patient and family, (82) including depression, (55) anxiety, (53) delirium (54) and cognitive impairment. (68, 84) (See Domain 2: Physical Aspects of Care).
- Regular, ongoing assessment of psychological reactions (83) (including but not limited to stress, anticipatory grieving and coping strategies) and psychiatric conditions occurs and is documented. (36) Whenever possible, a validated and context-specific assessment tool should be used. (80, 84, 85)
- Psychological assessment includes patient understanding of disease, symptoms, side effects and their treatments, as well as assessment of caregiving needs, capacity and coping strategies. (13, 81, 83, 86)
- Psychological assessment includes family understanding of the illness and its consequences for the patient as well as the family; assessment of family caregiving capacities, needs and coping strategies. (13, 21, 81, 83, 84, 87)
- Family is educated and supported to provide safe and appropriate psychological support measures to the patient. (21, 87)
- Pharmacologic, nonpharmacologic and complementary therapies are employed in the treatment of psychological distress or psychiatric syndromes, as appropriate. (84) Treatment alternatives are clearly documented and communicated and permit the patient and family to make informed choices. (13)
- Response to symptom distress is prompt and tracked, through documentation in the medical record. Regular reevaluation of treatment efficacy and patient-family preferences is documented. (36)
- Referrals to health care professionals with specialized skills in age-appropriate psychological and psychiatric management are made available when appropriate (e.g., psychiatrists, psychologists and social workers). Identified psychiatric comorbidities in family or caregivers are referred for treatment. (37)
- Developmentally appropriate assessment and support is provided to pediatric patients, their siblings, and the children or grandchildren of adult patients. (35)
- Communication with children and cognitively impaired individuals occurs using verbal, nonverbal and/or symbolic means appropriate to developmental stage and cognitive capacity.

- Treatment decisions are based on goals of care, assessment of risk and benefit, best evidence and patient/family preferences. The goal is to address psychological needs, treat psychiatric disorders, promote adjustment, and support opportunities for emotional growth, healing, reframing, completion of unfinished business and support through the bereavement period. (83-87)
- A process for quality improvement and review of psychological and psychiatric assessment and effectiveness of treatment is documented and leads to change in clinical practice. (17)

Guideline 3.2 A grief and bereavement program is available to patients and families, based on the assessed need for services. (88)

Criteria:

- The interdisciplinary team includes professionals with patient-population-appropriate education and skill in the care of patients and families experiencing loss, grief and bereavement. (14, 89)
- Bereavement services are recognized as a core component of the palliative care program. (88, 90-93)
- Bereavement services and follow-up are made available to the family for at least 12 months, or as long as is needed, after the death of the patient. (93)
- Grief and bereavement risk assessment is routine, developmentally appropriate and ongoing for the patient and family throughout the illness trajectory, recognizing issues of loss and grief in living with a life-threatening illness. (92)
- Clinical assessment is used to identify people at risk of complicated grief and bereavement, and its association with depression and comorbid complications, particularly among the elderly. (88, 90, 92, 93)
- Information on loss and grief and the availability of bereavement support services, including those available through hospice and other community programs, is made routinely available to families before and after the death of the patient, as culturally appropriate and desired. (90)
- Support and grief interventions are provided in accordance with developmental, cultural and spiritual needs, expectations and preferences of the family, including attention to the needs of siblings of pediatric patients and children of adult patients. (91)
- Staff and volunteers who provide bereavement services receive ongoing education, supervision and support. (47, 94)
- Referrals to health care professionals with specialized skills are made when clinically indicated. (37)

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NHPCO Standards {BCS 1, 2.1, 2.2, 2.3, 3.4; CCS 5.4; IDT 1, 1.1, 1.6, 3.3, 5.1, 6.3; PI 4, 4.1, 4.3, 4.4, 5.2, 6}[1]

[1] References from sections of the National Hospice and Palliative Care Organization Standards of Practice for Hospice Programs (2002) are cited in brackets, using their abbreviations as follows:

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CCS	Clinical Care and Services	HIF	Hospice Inpatient Facility
HR	Human Resources	NF	Nursing Facility Hospice Care
IDT	Interdisciplinary Team	HRCF	Hospice Residential Care Facility
LG	Leadership and Governance		

Domain 4: Social Aspects of Care

Guideline 4.1 Comprehensive interdisciplinary assessment identifies the social needs of patients and their families, and a care plan is developed in order to respond to these needs as effectively as possible. (95)

Criteria:

- The interdisciplinary team includes professionals with patient-population-specific skills in the assessment and management of social and practical needs during a life-threatening or chronic debilitating illness. (14)
- Practitioners skilled in the assessment and management of the developmental needs of children should be available for pediatric patients and the children of adult patients, as appropriate. (35)
- A comprehensive interdisciplinary social assessment is completed and documented, to include: family structure and geographic location; relationships; lines of communication; existing social and cultural networks; perceived social support; medical decision-making; work and school settings; finances; sexuality; intimacy; living arrangements; caregiver availability; access to transportation; access to prescription and over-the-counter medicines and nutritional products; access to needed equipment; community resources including school and work settings; and legal issues. (8, 9, 12, 13, 20, 21, 35, 36, 38, 96-100) (See Domain 6: Culture).
- Routine patient and family meetings (101) are conducted with members of the interdisciplinary team to assess understanding and address questions, provide information and help with decision-making, discuss goals of care and advance care planning, determine wishes, preferences, hopes and fears, provide emotional and social support and enhance communication.
- The social care plan is formulated from a comprehensive social and cultural assessment and reassessment, and reflects and documents values, goals and preferences as set by patient and family over time. (8, 20) Interventions are planned to minimize adverse impact of caregiving on the family and to promote caregiver and family goals and well-being. (21)
- Referrals to appropriate services are made that meet identified social needs and promote access to care, help in the home, school or work, transportation, rehabilitation, medications, counseling, community resources and equipment. (38)

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