

NQF

NATIONAL QUALITY FORUM

**A National
Framework and
Preferred Practices
for Palliative and
Hospice Care
Quality**

A
CONSENSUS
REPORT

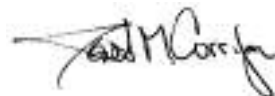
NATIONAL QUALITY FORUM

Foreword

The National Quality Forum (NQF) has acknowledged the increasingly important role of palliative care and hospice services by identifying them as national priority areas for healthcare quality improvement. A comprehensive set of performance metrics is needed to gauge our progress in these clinical areas; unfortunately, there are many measure and research gaps that prevent a thorough assessment of palliative care and hospice quality.

The palliative care and hospice framework endorsed in this report is intended as the first step in creating a comprehensive quality measurement and reporting system for palliative care and hospice services. The framework also served as a road map for the identification of a set of NQF-endorsed™ preferred practices aimed at improving palliative and hospice care across the Institute of Medicine's six dimensions of quality – safe, effective, timely, patient centered, efficient, and equitable.

We thank the Review Committee for its dedication to improving palliative and hospice care, and we thank NQF Members for their collective commitment to improving healthcare quality through their approval of the framework and practices.



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President and Chief Executive Officer

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ISBN 1-933875-06-2

Printed in the U.S.A.

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A National Framework and Preferred Practices for Palliative and Hospice Care Quality

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NATIONAL QUALITY FORUM

A National Framework and Preferred Practices for Palliative and Hospice Care Quality

Executive Summary

The number of palliative care and hospice programs has grown rapidly in recent years, as a result of the recognition of the unique constellation of skills that are required to manage the symptoms and needs of seriously sick patients, including those who are terminally ill, and the growth in the population living with chronic, debilitating diseases. Although the provision of this specialized care occurs at all levels of the healthcare system, it frequently requires the input of specialized teams. The National Quality Forum (NQF) acknowledged the importance of palliative care and hospice programs when it made them national priority areas for healthcare quality improvement.¹

In order to ensure that palliative care and hospice services are of the highest quality, NQF envisions a quality measurement and reporting system focused on these critical areas. As a first step in deriving this system, NQF, with support from the Robert Wood Johnson Foundation and the Department of Veterans Affairs, has endorsed a framework to guide the selection of a comprehensive measure set and a set of preferred practices related to palliative and hospice care. Also identified are areas where research is required to fill the gaps in a measurement system.

In developing the framework, which used the National Consensus Project for Quality Palliative Care's (NCP's) *Clinical Practice Guidelines for Quality Palliative Care* as the starting point, NQF used the following definitions:

¹National Quality Forum (NQF), *National Priorities for Healthcare Quality Measurement and Reporting: A Consensus Report*, Washington, DC: NQF; 2004.

Palliative care refers to patient- and family-centered care that optimizes quality of life by anticipating, preventing, and treating suffering. Palliative care throughout the continuum of illness involves addressing physical, intellectual, emotional, social, and spiritual needs and facilitating patient autonomy, access to information, and choice.

Hospice care is a service delivery system that provides palliative care for patients who have a limited life expectancy and require comprehensive biomedical, psychosocial, and spiritual support as they enter the terminal stage of an illness or condition. It also supports family members coping with the complex consequences of illness, disability, and aging as death nears. Hospice care further addresses the bereavement needs of the family following the death of the patient.

Of particular importance, palliative care services are indicated across the entire trajectory of a patient's illness and its provision should not be restricted to the end-of-life phase.

The palliative care and hospice framework that is presented in the first chapter of this report provides the foundation upon which a quality measurement and reporting system should be built. It identifies 12 structural and programmatic elements as essential to the performance of sound programs: interdisciplinary teams; diverse models of delivery, bereavement programs; educational programs; patient and family education; volunteer programs; quality assessment/performance improvement; community outreach programs; administrative policies; information

technology and data gathering; methods for resolving ethical dilemmas; and personnel self-care initiatives.

The framework served as a road map for the identification of a set of NQF-endorsed™ preferred practices, presented in chapter 2, that should fulfill the needs of a comprehensive evaluation and reporting program and ensure that palliative and hospice care are safe, beneficial, timely, patient centered, efficient, and equitable. Over the past three decades, barriers and facilitators to the provision of optimal palliative and hospice care have been studied, developed, and identified. And although palliative and hospice care programs ultimately respond to the unique demands of their local communities, a set of preferred practices can serve as the building blocks for high-quality programs across many practice settings and as the basis for developing performance measures.

The 38 preferred practices presented in this report (see table 1) have been endorsed as suitable for implementation by palliative care and hospice programs. They were derived from NCP's eight domains of quality palliative and hospice care:

- structures and processes of care;
- 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.

Finally, during the course of this study, gaps in the knowledge base addressing palliative and hospice care were identified. An agenda for further research is presented

in chapter 3 in the hope that this will expedite the development of a comprehensive measurement and reporting system for palliative care and hospice services.

Table 1 – Preferred Practices

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 healthcare professional(s).
 2. Provide access to palliative and hospice care that is responsive to the patient and family 24 hours a day, 7 days a week.
 3. Provide continuing education to all healthcare professionals on the domains of palliative care and hospice care.
 4. Provide adequate training and clinical support to assure that professional staff are confident in their ability to provide palliative care for patients.
 5. Hospice care and specialized palliative care professionals should be appropriately trained, credentialed, and/or certified in their area of expertise.
 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.
 7. Ensure that upon transfer between healthcare 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.
 8. Healthcare professionals should present hospice as an option to all patients and families when death within a year would not be surprising and should reintroduce the hospice option as the patient declines.
 9. Patients and caregivers should be asked by palliative and hospice care programs to assess physicians'/healthcare professionals' ability to discuss hospice as an option.
 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.
 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.
 12. Measure and document pain, dyspnea, constipation, and other symptoms using available standardized scales.
 13. Assess and manage symptoms and side effects in a timely, safe, and effective manner to a level that is acceptable to the patient and family.
 14. Measure and document anxiety, depression, delirium, behavioral disturbances, and other common psychological symptoms using available standardized scales.
 15. Manage anxiety, depression, delirium, behavioral disturbances, and other common psychological symptoms in a timely, safe, and effective manner to a level that is acceptable to the patient and family.
 16. Assess and manage the psychological reactions of patients and families (including stress, anticipatory grief, and coping) in a regular, ongoing fashion in order to address emotional and functional impairment and loss.
 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.
 18. Conduct regular patient and family care conferences with physicians and other appropriate members of the interdisciplinary team to provide information, to discuss goals of care, disease prognosis, and advance care planning, and to offer support.
 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, decisionmaking, work and school settings, finances, sexuality/intimacy, caregiver availability/stress, and access to medicines and equipment.
 20. Develop and document a plan based on an assessment of religious, spiritual, and existential concerns using a structured instrument, and integrate the information obtained from the assessment into the palliative care plan.
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Table 1 – Preferred Practices (continued)

21. Provide information about the availability of spiritual care services, and make spiritual care available either through organizational spiritual care counseling or through the patient's own clergy relationships.
 22. Specialized palliative and hospice care teams should include spiritual care professionals appropriately trained and certified in palliative care.
 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.
 24. Incorporate cultural assessment as a component of comprehensive palliative and hospice care assessment, including but not limited to locus of decisionmaking, preferences regarding disclosure of information, truth telling and decisionmaking, 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.
 25. Provide professional interpreter services and culturally sensitive materials in the patient's and family's preferred language.
 26. Recognize and document the transition to the active dying phase, and communicate to the patient, family, and staff the expectation of imminent death.
 27. Educate the family on a timely basis regarding the signs and symptoms of imminent death in an age-appropriate, developmentally appropriate, and culturally appropriate manner.
 28. As part of the ongoing care planning process, routinely ascertain and document patient and family wishes about the care setting for the site of death, and fulfill patient and family preferences when possible.
 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.
 30. Treat the body after death with respect according to the cultural and religious practices of the family and in accordance with local law.
 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.
 32. Document the designated surrogate/decisionmaker in accordance with state law for every patient in primary, acute, and long-term care and in palliative and hospice care.
 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.
 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 hospital care, through a program such as the Physician Orders for Life-Sustaining Treatment (POLST) program.
 35. Make advance directives and surrogacy designations available across care settings, while protecting patient privacy and adherence to HIPAA regulations, for example, by using Internet-based registries or electronic personal health records.
 36. Develop healthcare and community collaborations to promote advance care planning and the completion of advance directives for all individuals, for example, the Respecting Choices and Community Conversations on Compassionate Care programs.
 37. Establish or have access to ethics committees or ethics consultation across care settings to address ethical conflicts at the end of life.
 38. For minors with decisionmaking capacity, document the child's views and preferences for medical care, including assent for treatment, and give them appropriate weight in decisionmaking. Make appropriate professional staff members available to both the child and the adult decisionmaker for consultation and intervention when the child's wishes differ from those of the adult decisionmaker.
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NATIONAL QUALITY FORUM

Chapter 1 Framework

Introduction

The number of palliative care and hospice programs has grown rapidly in recent years in response both to growth in the population living with chronic, debilitating, and life-threatening illness and injury^{1,2,3,4,5} and to clinician interest in effective approaches to the care of such patients.^{6,7,8,9,10} Palliative care focuses on the relief of suffering and support for the best possible quality of life for patients with serious and complex chronic illness, as well as for their families.* In practice, palliative care involves the assessment and treatment of pain and other symptoms; expert communication with patients, families, and other health professionals about the goals of medical care¹¹ and the decisions and treatments that would support those goals; the assurance of quality communication and coordination across care settings and through disease transitions; the provision of psychosocial support; and consistent attention to quality of life.¹² Pain management and end-of-life care are 2 of the 23 National Quality Forum (NQF)-endorsedTM national priority areas for healthcare quality improvement. As such, these areas represent high priorities for the identification of goals and targets to achieve high-quality care, which, in turn, should result in the endorsement of measures to assess palliative and hospice care quality. This framework[†] is a first step toward this end.

* The patient's family should be defined by the patient and respected by all providers. When a surrogate decisionmaker is designated, this individual should receive the same educational and support services that would have been provided to the patient and the family.

† The National Consensus Project for Quality Palliative Care's (NCP's) publication *Clinical Practice Guidelines for Quality Palliative Care* (NCP Guidelines) was the starting point for this framework. The NCP Guidelines provided an exposition of the fundamental approach, requisite capabilities, and desired outcomes for viewing the full spectrum of palliative care services. This document expands on certain areas and also is structured to provide a comprehensive framework for palliative and hospice care quality measurement and reporting.

Integrating palliative and life-prolonging interventions into general care presents a major challenge for healthcare in the United States. Because palliation is a critical dimension of healthcare, all patients should have access to primary healthcare practitioners who are skilled and knowledgeable about basic palliative therapies. All physicians need to know when the services of interdisciplinary specialist-level palliative care clinicians are indicated and how to access them. In other cases, a patient or his or her family may request, require, or be referred to the services of palliative care specialists. When a patient moves into the late stages of a life-threatening or debilitating illness or injury, the relative need for palliative care increases and access to hospice programs should be enhanced to ensure that comprehensive and high-intensity palliative care is available during this stage of illness and during family bereavement. Such an approach should provide all patients with an integrated approach to treatment that looks to quality of life, as well as to quality of care, throughout their experience with the healthcare system.

A central tenet of palliative care is that the needs of patients[‡] and families should be met by a genuine partnership between palliative care and hospice programs. Close coordination and partnerships between palliative care and hospice programs support the continuity of palliative care throughout the course of illness and across the continuum of care settings. Comprehensive hospice care often best

meets the complex and intensive terminal care needs of most patients and families facing the end of life.

To ensure that palliative care and hospice services are of the highest quality, it is essential to develop and endorse voluntary consensus standards, including validated performance measures, that can be used in evaluating, monitoring, and reporting the quality of care. The framework presented in this chapter represents the first step in this process and provides the foundation for a comprehensive program of palliative and hospice care performance evaluation. It serves as the road map for identifying a set of NQF-endorsed preferred practices and measures that should fulfill the needs of a comprehensive evaluation and reporting program to ensure that palliative and hospice care are safe, beneficial, timely, patient centered, efficient, and equitable (see chapter 2). Chapter 3 provides recommendations on high-priority research issues.

Definitions

Palliative care is both a philosophy of care and an organized, highly structured care delivery system. Palliative care can be delivered concurrently with life-prolonging care or as the main focus of care.^{13,14} It begins at the time of diagnosis of a life-threatening or debilitating illness or injury and continues into the family's bereavement period.^{6,7,8,9,10,15} Palliative care continues from the time of diagnosis as long as the conditions and their treatments pose significant burdens until a reversal is achieved or death results.

[‡] While actual application may vary, the framework should be considered equally appropriate to both children and adults.

For purposes of this framework, palliative care is defined as follows:

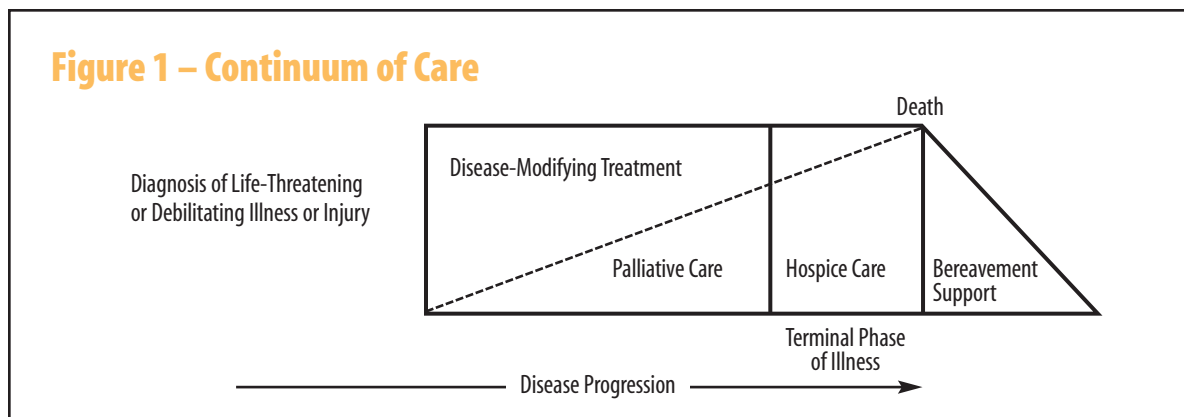
Palliative care refers to patient- and family-centered care that optimizes quality of life by anticipating, preventing, and treating suffering. Palliative care throughout the continuum of illness involves addressing physical, intellectual, emotional, social, and spiritual needs and facilitating patient autonomy, access to information, and choice.[§]

An important phase in the spectrum of palliative care services is end-of-life care, which applies when a patient's course of illness is determined to be progressing toward death and disease-specific, life-prolonging interventions are no longer appropriate, effective, or desired. End-of-life care seeks to achieve a "good death," both for patient and family, as manifested by successful distress management across all dimensions of care, including the bereavement period. The Institute of Medicine (IOM) defines a "good death" as

one that is "free from avoidable distress and suffering for patients, families, and caregivers; in general accord with the patient's and family's wishes; and reasonably consistent with clinical, cultural, and ethical standards."¹⁶ The structural and process attributes of hospices are specifically geared to achieve a "good death." For purposes of this NQF-endorsed framework, hospice care is defined as follows:

Hospice care is a service delivery system that provides palliative care for patients who have a limited life expectancy and require comprehensive biomedical, psychosocial, and spiritual support as they enter the terminal stage of an illness or condition. It also supports family members coping with the complex consequences of illness, disability, and aging as death nears. Hospice care further addresses the bereavement needs of the family following the death of the patient.

Figure 1 delineates the continuum for palliative and hospice care.



[§] Defined by the Centers for Medicare and Medicaid Services in its proposed Hospice Conditions of Participation and as adapted from the World Health Organization.¹³

Purpose

The purpose of this NQF-endorsed framework for palliative and hospice care quality measurement and reporting is to provide a supporting structure for the future identification, organization, and endorsement of national voluntary consensus standards that will provide the necessary data for consumers, purchasers, and healthcare professionals to make informed decisions and to improve quality of care. In addition, the framework provides a structured perspective for evaluating the development, expansion, and modifications of new and existing palliative care services.

In deriving this framework, a major emphasis has been placed on identifying those aspects of quality palliative care that may be best achievable by specialized palliative care and hospice programs. Many aspects of palliative care are performed across diverse healthcare settings, under the direction of both specialized and non-palliative care specialist professionals. Therefore, many precepts of this framework also will apply directly to the healthcare services provided by these non-specialists.

As noted below under the section on the scope of palliative and hospice care, the populations requiring palliative services are broad and diverse, with management issues that are unique to their clinical situations. Examples include the pediatric population, the vulnerable elderly, and the mentally disadvantaged. The elements of this framework were crafted to apply broadly to all groups, with the recognition that in some instances unique features of

the population will require that modifications be made in order to ensure that their particular needs are met. In addition, the specialized needs of these patients may require professionals with expertise not only in palliative care services but also in the management of the specific populations.

Goals

The goals of palliative and hospice care are as follows:

- Address pain and symptom control, psychosocial distress, spiritual issues, and practical needs with the patient and family throughout the continuum of care.
- Promote advance care planning and the application of the principles of palliative care by healthcare professionals in all settings (primary and specialty care, acute care, and long-term care).^{**}
- Provide patients and families with the information they need in an ongoing and understandable manner, so that they can grasp their condition and treatment options. This includes eliciting their values and goals over time; regularly reassessing the benefits and burdens of treatment; and ensuring that the decisionmaking process about the care plan is sensitive to changes in the patient's condition.
- Ensure genuine coordination and continuity of care across settings through regular, high-quality communication among healthcare professionals at times of transition or changing needs and through the provision of effective continuity of care that utilizes the techniques of case management.

^{**} See also, National Quality Forum (NQF), *Safe Practices for Better Healthcare: A Consensus Report*, Washington, DC: NQF; 2003.

- Prepare both the patient and the family for the dying process and for death, when it is anticipated; explore hospice options and ensure that opportunities for personal growth are enhanced and that bereavement support is available for the family; and continue bereavement support for the family beyond the patient's death.
- Deliver palliative care through an organized structure that promotes a patient/family-centered model of interdisciplinary team care.

General Principles

Fifteen general principles represent the underlying basis for the provision and delivery of palliative care and hospice care. They constitute a philosophy of care across all settings, healthcare professionals, recipients of care, and domains of care. The goals and the philosophy of care for palliative care and hospice care are linked.

The general principles that should guide the provision of high-quality palliative and hospice care are as follows:

- Palliative and hospice care are patient centered and family centered.
- Palliative and hospice care provide information to support decisionmaking and to ensure that patient and family values and preferences are treated with respect.
- Palliative and hospice care providers are sensitive to the cultural, spiritual, and social values and preferences of the patients and families they serve.
- Palliative and hospice care support decisionmaking that enables patients and families to work toward their goals for the remaining days of life.
- Palliative and hospice care address the total needs of patients, including symptom control, psychosocial distress, spiritual issues, and the social, practical, financial, and legal ramifications of their condition.
- High-quality palliative and hospice care requires the services of a coordinated interdisciplinary team.
- Interdisciplinary palliative and hospice care teams are educated to possess the communication skills needed to effectively share information, elicit goals and preferences, and provide support for medical decisionmaking.

- Interdisciplinary palliative and hospice teams are skilled in providing care to the suffering, the dying, and the bereaved.
- Interdisciplinary palliative and hospice teams are skilled at assessing and treating physical and psychological symptoms and managing the side effects associated with patients' diseases and treatments.
- Palliative and hospice care are administered across all healthcare settings. Ensuring the coordination of care between the primary medical team and specialized palliative and hospice services is a critical element of providing optimal care.
- Equitable access to palliative and hospice care is available across all ages; prognoses; and patient populations; diagnostic categories; healthcare settings; and geographical areas, regardless of race, ethnicity, sexual orientation, or ability to pay.
- In order to provide care of the highest quality, the processes of hospice and palliative care are regularly and systematically evaluated and outcomes data are measured using validated instruments. Systematically collected data should be used for formal quality improvement programs.
- Palliative and hospice professionals act as advocates when addressing regulatory, legal, and legislative issues affecting the delivery of high-quality palliative care.
- Palliative and hospice care programs for unique populations (e.g., prison populations, those in Intermediate Care Facilities for the Mentally Retarded [ICFMR], the physically disabled, and those with dual diagnoses) assess any need for specialized services and have the capability for delivering services or knowledge of how to access specialized services in a timely manner.
- Research and education are supported to promote preferred practices in the delivery of palliative and end-of-life care.

Scope

The scope of palliative and hospice care defines the boundaries of such care within the healthcare system and indicates what is included under the rubric of palliative and hospice care so that quality-oriented preferred practices and measures can be derived.

Populations to Be Served

The populations of those with life-threatening or debilitating illness or injury are assumed to encompass patients of all ages within a broad range of diagnostic categories who are living with a persistent or recurring condition that adversely affects their daily functioning or that will predictably reduce life expectancy. Hospice care focuses on patients who are entering the terminal stages of their illness. The patient populations include the following:

- Children and adults with congenital injuries or conditions leading to dependence on life-sustaining treatments and/or long-term care by others for support of the activities of daily living.
- Persons of any age with acute, debilitating, and/or life-threatening illnesses or injuries, where cure or reversibility is a realistic goal and the conditions themselves and their treatments may pose significant burdens.
- Persons with life-threatening illness who choose not to undergo disease-oriented, life-prolonging treatment and request palliative or hospice care.
- Persons living with progressive chronic conditions.
- Persons living with chronic and life-limiting injuries from accidents or other forms of trauma.
- Seriously and terminally ill patients who are unlikely to recover or stabilize and for whom intensive palliation is the predominant focus and goal of care for the remaining time.

Care Settings

Palliative and hospice care should be administered across all care settings, including acute care or rehabilitation hospital inpatient; chronic care facility inpatient; hospice inpatient/residence; nursing home or other congregate living facility; physician office/clinic outpatient; and the home.

Levels of Healthcare Professionals

Palliative care is provided at two levels in the healthcare system: the primary care level and the specialty level. The delivery of care at two levels carries with it a set of requirements for professional education and training. For primary care, palliative care is provided by the healthcare team responsible for the routine care of the patient's life-threatening or debilitating illness or injury. In the area of specialty care, palliative and hospice care are provided by an interdisciplinary team of appropriately trained and credentialed physicians, nurses, social workers, spiritual care counselors, and others whose expertise is required to optimize the quality of life for those with life-threatening or debilitating illness or injury.

The specialties of palliative and hospice care require defined areas of expertise, skill, and self-regulation. In addition, all healthcare professionals, in the routine course of providing healthcare services, are expected to be adequately trained to provide basic elements of palliative care—for example, pain and symptom assessment and management and advance care planning. (Primary practitioners may include

medical specialists responsible for the care of patients with life-threatening or debilitating illness or injury.)

Palliative and hospice care are evolving fields that are moving increasingly toward professional accreditation.¹⁷ The goal is to have palliative and hospice care provided by a team composed of health professionals, each certified in her or his discipline.¹⁷

Structural and Programmatic Elements

A broad range of structural and programmatic elements form the basis for assessing whether the system for delivering care is capable of ensuring that the basic processes of high-quality palliative and hospice care can be implemented. A high-quality program should address the 12 elements described below.

Interdisciplinary Teams

The provision of specialized palliative and hospice care must be broad in order to meet the complex needs of the palliative care population. A palliative care team includes a core group of professionals from medicine, nursing, and social work. It may include some combination of volunteer coordinators; bereavement coordinators; spiritual care counselors; psychologists; pharmacists; nursing assistants; home attendants; dietitians; physical, occupational, art, play, music, and child life therapists; case managers; and trained volunteers. Hospice programs strive to include the services of all of these groups.

Models of Care Delivery

Palliative and hospice care can be delivered in a variety of care settings, including the home, with staffing by varied constellations of professional caregivers. All of the following are current models for delivery of care, and it is anticipated that other models and innovations in care delivery will be developed:

- The **inpatient setting** includes acute or rehabilitation hospitals, dedicated hospice and/or palliative care units in a hospital (including scatter beds), free-standing hospice and/or palliative care units, and hospice and/or palliative care provided in other inpatient settings.
- The **consultation team setting** includes the hospital, the outpatient clinic or office practice, nursing homes, care provided at home through home health or hospice, and other settings in which a consultation team would be appropriate.
- The **outpatient care setting** includes outpatient clinics and physician office practices.
- The **home care setting** includes palliative home health, hospice at home, and other services provided at home.
- The **residential living setting** includes nursing homes, assisted living, boarding care, ICFMR, and correctional facilities.

A combination of the above services can be used to meet the needs of patients and families.

Bereavement Programs

All palliative and hospice care models should encompass structured programs to support grieving family members and

should recognize the burden that falls upon family caregivers and subsequent problems that may develop after these services are completed. It is recommended that palliative and hospice care models include bereavement support extending at least 13 months beyond the patient's death.

Educational Programs

Palliative and hospice care programs require ongoing professional education for all palliative care professionals in the knowledge, attitudes, and skills required to deliver quality palliative care across all domains.

- **Professional programs.** Palliative and hospice care programs should have educational and professional orientation and training programs to ensure that all health-care professionals are proficient in their areas of expertise.
- **Volunteer programs.** Palliative and hospice care programs should have structured orientation, educational, and training programs to ensure that all volunteers are adequately supervised and can interact with patients and families in a knowledgeable and appropriate manner.

Patient and Family Education

Palliative and hospice care programs should have a fully developed program of patient and family education that includes an array of written and visual materials related to all domains of palliative care and culturally appropriate mechanisms for education for those of limited literacy or who are non-English speaking.

Volunteers

Palliative care programs may enlist and utilize the services of appropriately trained and supervised volunteers to assist in the support of patients and families. In some palliative care settings, volunteers can serve as important components for providing comprehensive care. Hospice care programs should enlist and utilize the services of appropriately trained and supervised volunteers to assist in the support of patients and families.

Quality Assessment/Performance Improvement (QA/PI)

A palliative or hospice care program must have a formal QA/PI program in place that actively uses data for continuous performance improvement and that supports preferred practices. QA/PI programs for advance care planning, palliative care, and pain management should be developed and integrated into current QA/PI programs for primary care practices.

Community Outreach Programs

The goals and aims of palliative and hospice care should be broadly understood by the entire community. Toward this end, community outreach programs to educate and inform the general population should be initiated and maintained.

Administrative Policies

All of the following administrative policies are essential to all palliative and hospice care programs:

- confidentiality;
- intake and discharge;
- coordination of care and referrals;^{††}
- pharmacy and medication documentation; and
- infection control and safety.

Information Technology and Data Gathering

Palliative and hospice care programs should utilize both validated forms and surveys for symptom assessment and client (family and patient) satisfaction and databases to facilitate the ongoing monitoring of activities and the tracking of trends in quality improvement initiatives.

Resolving Ethical Dilemmas

Palliative and hospice care programs should establish a policy and structure for resolving ethical dilemmas, including ethics committees, mediation and conflict resolution, policy development, and staff education.

^{††} NQF's recently endorsed *National Voluntary Consensus Standards for Ambulatory Care: Part 1* (in press) contains a standardized definition of care coordination and a framework for measuring care coordination.

Self-Care Initiatives

Palliative and hospice care professionals and healthcare providers should use self-care measures to prevent and alleviate professional burn-out and psychosocial, mental, physical, and spiritual burdens while caring for seriously ill patients and their families.

Domains

The aim of this framework is to serve as a foundation for identifying preferred practices of palliative and hospice care and for developing and implementing a measurement and reporting system that encompasses the entire spectrum of services, activities, and structural requirements of this broad area of healthcare. The NCP identified eight domains that allow the systematic appraisal of the multifaceted aspects of palliative care. For each domain, specific guidelines for professional behavior and service delivery are delineated.

The eight domains of quality palliative and hospice care are as follows:

1. structures 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; and
8. ethical and legal aspects of care.

Most of the framework elements for each domain apply to both palliative care and hospice care. In certain areas where the application is to only one of these elements, the focus is specified.

Domain 1. Structures and Processes of Care

Domain 1.1. Structures of Care

- Palliative and hospice care are provided by healthcare professionals who have the knowledge, skills, and attitudes to meet the needs of their patients and families.^{18,19}
- The interdisciplinary team consists of professionals with the education, skills, expertise, and competence to assess and treat the specific palliative care needs of the patient.^{20,21}
- An appropriately trained interdisciplinary team provides services to the patient and family, consistent with a comprehensive care plan.^{22,23}
- The interdisciplinary team may include appropriately trained and supervised volunteers.^{24,25,26,27,28}
- Support for education and training is available to the interdisciplinary team.^{29,30,31}
- The palliative care and hospice programs are committed to data-driven quality improvement in clinical and management practices.^{32,33,34}
- The palliative or hospice care program recognizes the emotional impact on the palliative care team of providing care to patients with life-threatening or debilitating illnesses or injuries and their families and provides appropriate support and resources for the team.²³

- Palliative care programs should have a collaborative relationship with one or more hospices and other community resources in order to ensure continuity of access to the highest quality palliative care and/or hospice care that fits the needs of the patient across the illness trajectory.^{34,23}
- The setting of care should meet the preferences, needs, and circumstances of the patient and family to the extent possible.^{34,23}
- In rural areas where accessing specialized care is difficult, organizations should institute telehealth and telemedicine communications.

Domain 1.2. Processes of Care

- The plan of care is based on a comprehensive interdisciplinary assessment (e.g., including adequacy of diagnosis and treatment, consistent with review of past history, diagnostic tests, and responses to past treatments) of the patient and family.⁴
- The care plan is based on expert clinical knowledge of the pathophysiological and treatment aspects of illness, informed by the identified values, goals, and needs of the patient and family.⁴
- The care plan is patient centered, is developed with professional guidance, and supports patient/family decision-making.³⁵
- The care plan evolves as necessary in accordance with the changing needs of the patient and family.³⁵

- Effective communication occurs regularly both among healthcare professionals and with the patient and family to ensure that patients and families can make decisions based on the information received and that healthcare professionals can develop care plans that are patient and family centered.³⁵
- The special needs of children (either as patients or as family members of patients) must be addressed and met by the palliative or hospice care team.³⁵

Domain 2. Physical Aspects of Care

- Symptoms and side effects are managed in a timely, safe, and effective manner.¹⁶
- Symptoms and side effects are managed using the best available evidence.^{16,36,37}
- Symptoms and side effects are managed by healthcare professionals with the appropriate technical skills and training.^{23,38}
- Symptom and side effect management is done in a manner that is patient and family centered.^{39,40}

Domain 3. Psychological and Psychiatric Aspects of Care

- Psychological and psychiatric issues are assessed and managed in a timely, safe, and effective manner.^{41,42}
- Psychological and psychiatric issues are assessed and managed based upon the best available evidence.⁴³
- Psychological and psychiatric issues are managed in a manner that is acceptable to the patient and family.^{39,40}
- A grief and bereavement program is available to patients, families, and staff.^{44,45,46}

Domain 4. Social Aspects of Care

- A comprehensive interdisciplinary assessment identifies the social needs of patients and families.^{47,48}
- A care plan is developed in order to effectively respond to patient and family social needs.^{47,48}

Domain 5. Spiritual, Religious, and Existential Aspects of Care

- Spiritual, religious, and existential dimensions of care are assessed and receive a response based upon the best available evidence.^{39,49}
- Spiritual, religious, and existential dimensions are approached in a manner that is acceptable to the patient and family as they pertain to the patient's illness.^{39,49}

Domain 6. Cultural Aspects of Care

Palliative and hospice care programs assess and attempt to meet the needs of the patient, family, and community in a culturally sensitive manner.^{50,51}

Domain 7. Care of the Imminently Dying Patient

Signs and symptoms of impending death are recognized and communicated, and care appropriate for the phase of illness is provided.^{35,52,53}

Domain 8. Ethical and Legal Aspects of Care

- The patient's goals, preferences, and choices are respected within the current principles of biomedical ethics, generally accepted standards of medical care, and the applicable state and federal law, and they form the basis for the plan of care.^{35,52,53}
- Processes will be in place to manage ethical aspects involving discordant patient, family, and caregiver goals and to handle disputes and uncertainties regarding a patient's previously stated preferences and current family or proxy decisions.

- Healthcare professionals will weigh and attempt to incorporate the values, goals, and preferences of patients whose decisional capacity is limited by illness, younger age, developmental disability, severe mental illness, dementia, and other conditions. When necessary, ethics consultations should be available.^{35,52,53}
- The palliative or hospice care program is knowledgeable about the legal, regulatory, and ethical aspects of palliative care.^{54,55,56}
- The palliative or hospice care program is aware of and addresses the complex ethical issues arising in the care of persons with life-threatening and/or debilitating illness or injury.^{57,58,59}

Levels of Measurement

The delivery of palliative care and hospice care requires the integration of services from several levels of the healthcare system. The achievement of comprehensive high-quality palliative care requires appropriate performance and outcomes at three levels: the patient/family-centered care level, the organizational/programmatic level, and the system level. These are not mutually exclusive; measures used at one level also may be used at another.[#]

Patient/Family-Centered Care Level

Measures of quality at this level center on care that directly affects patient outcomes (e.g., management of symptoms such as pain). Some outcomes that are measured at this level can be aggregated to describe characteristics of patient care units or organizations. For example, pain levels and survival rates can be computed from individual measures to describe outcome measures for an intensive care unit or for a total hospital. Thus, the adequacy of pain control can be assessed at the patient/family level (i.e., did a specific patient receive optimal care?) and at the organizational level (i.e., do average pain levels indicate that the patient population at a given hospital receives adequate care?).

[#] The mission of NQF is to improve American healthcare through the endorsement of consensus-based national standards for the measurement and public reporting of healthcare performance data.

Organizational/Programmatic Level

Organizations can be assessed using structural, process, and/or patient outcome measures applicable to patients and families served by that organization—for example, staff-patient ratios, the operation of a bereavement program, and time in hospice before death. Organizational- or system-level measures are used for organizational decisionmaking and for guiding organizational improvements.

System Level

Measures at the system level (i.e., the greater community level, including local, regional, state, and national levels)—for example, the availability of hospice care; socioeconomic or cultural differences in care delivered; and the percentage of patients who die at home—can be used in healthcare planning and for determining the allocation of healthcare resources. Also, data from the patient and/or system levels can be further aggregated to obtain community, regional, or national measures of care.

Outcomes

A common framework used in health services research, including quality of care research, is that developed by Avedis Donabedian, who discussed the structures, process, and outcomes of care.⁶⁰ Structure is defined as the relatively enduring characteristics of the healthcare setting in which the care is delivered, and includes the type and ownership of the organization and the professional credentials of the

healthcare providers. Process is defined as what healthcare providers do to, for, or on behalf of patients and includes the interventions and programs of care. Patient outcomes refer to the characteristics of patients that are affected by what healthcare providers do for them or on their behalf. Thus, factors such as age and gender, which are patient characteristics, are not patient outcomes, since they are not affected by what the provider does. Characteristics such as pain and other symptoms, side effects of medications, nosocomial infections, quality of life, patient and family satisfaction, and mortality are representative of patient outcomes.

In palliative and hospice care, relevant patient outcomes include the control of symptoms and side effects, sufficient knowledge of the disease/condition to enable the patient to participate in his/her own care, optimum physical and psychological functioning, and optimum quality of life for the patient and family. The symptoms, side effects, and functional ability may differ by condition along with patient desires for their control. That is, for patients with cancer, pain control may be a relevant outcome, while for patients with chronic obstructive pulmonary disease, reduced dyspnea may be a more relevant outcome.

When patients near the end of life, several additional outcomes become relevant. IOM identified six general desirable outcomes of a “good death”: overall quality of life; physical well-being and functioning; psychosocial well-being and functioning; spiritual well-being; patient perceptions of

care; and family well-being and perceptions.¹⁶ The hospice care system defines four general outcomes: comfortable dying, self-determined life closure, safe dying, and effective grieving.⁶¹

In selecting outcomes for palliative and hospice care, the following attributes should be considered:

- The selection of appropriate outcomes for each domain of palliative care should relate to processes that address one of the NQF-endorsed quality aims – safety, benefit, equity, timeliness, patient-centeredness, and efficiency. The selected outcome will vary according to the area of evaluation.
- Preferred practices in palliative and hospice care should have demonstrated that they will produce desirable patient outcomes in one of the NQF-endorsed quality aims.
- End-of-life care outcomes address a special set of circumstances involving both patient and family and should focus on the achievement of a healthy, satisfying, functional environment in the face of a clinically downward course.

Preferred Practices

A preferred practice can be thought of as a best practice that, when executed effectively, leads to enhanced project performance.⁶² The activity should be practically defined – that is, it should not be excessively detailed to the level of technological minutiae or be so abstract that it does not provide practical information about the action to be taken. By definition, it must be linked to a specific, desired outcome. The designation of a preferred

practice is appropriate only when substantial research or documented experience demonstrates that the results are consistently achievable. In many instances, information exists that the preferred practice is superior to other processes or methods.

For the purposes of palliative and hospice care, preferred practices may apply both to the specific healthcare processes that lead to optimal outcomes and to the structural elements that have been demonstrated to facilitate the performance of the most effective processes of care or that are associated with optimal outcomes, including satisfaction with care (see appendix C).^{23,63,64,65,66,67,68}

Based on previously used NQF criteria, all of the following criteria should be used in selecting preferred practices for palliative and hospice care:

Specificity. The practice must be a clearly and precisely defined process or manner of providing a palliative or hospice care service.

Benefit. If the practices were widely used, they would improve the quality of life for patients and families who require palliative and hospice care services.

Evidence of effectiveness. There is clear-cut evidence that the practice would be effective in improving palliative and hospice care services.

Generalizability. The practice can be used in multiple applicable palliative and hospice care settings.

Readiness. The necessary technology and appropriately skilled staff must be available to most healthcare organizations.

Measurability. The availability of potential sources of data and the feasibility of meeting the technical aspects of measure development such as risk adjustment should be achievable within a reasonable timeframe.

Performance Measures

Quality measures are the quantification of the aspects of palliative and hospice care structures, processes, or outcomes that have been determined to represent high-quality care—that is, they represent or lead to optimal palliative care outcomes. A set of quality measures may be at least partially derived from a set of preferred practices.

A measure set for palliative and hospice care should be comprehensive and should permit assessment for identifying improvement areas in all aspects of care, including conditions, settings, and the clinical scenarios under which care is delivered. A comprehensive palliative and hospice care measure set should:

- address all of the NQF-endorsed quality aims for care that is safe, beneficial, patient centered, efficient, timely, and equitable;
- contain some cross-cutting measures that address the needs of all patients (i.e., pain is assessed and relieved);
- contain measures that apply to both primary care health-care professionals and specialists (i.e., assessment and treatment of depression, use of advance directives);
- contain some measures that can be applied across all palliative and hospice care settings, models of palliative and hospice care delivery, and types of specialist health-care professionals (i.e., pain assessment, identification of delirium, policies for resolution of family conflict);
- contain measures that assess coordination of care of hospices and palliative care programs with non-specialist providers, including hospitals; nursing facilities; primary care, medical, and surgical specialists; and disease management programs, for example, with regard to advance care planning and hospice referral;

- evaluate service quality for each phase of the palliative and hospice care patient-healthcare-professional interaction, including assessment, providing information, making decisions, planning care, delivering care, confirming results of care, and accounting for patient goals;
- address all domains of palliative and hospice care, including physical, psychological, social, spiritual, cultural, dying and bereavement, and legal and ethical;
- consist of standards for palliative and hospice care, including structural elements, process measures for palliative care practices, and outcome measures;
- address the needs of all groups of patients who require palliative and/or hospice care services; and
- address the preferences and needs of patients and families.

Using the Framework for Quality Measurement and Reporting

To monitor the comprehensiveness of a palliative or hospice care measure set and to identify areas for measure development and research, the following matrices are provided that represent templates for assessing the inclusion of the diverse dimensions listed above. For each area, measures addressing each of the NQF-endorsed aims of quality care should be endorsed or developed. (In assessing the status of measures for evaluating practitioner performance, the measures have been categorized according to the relevant type of patient-professional interaction.)⁶⁹ The aim of equitable care is a cross-cutting aim and applies to each cell in each matrix.

Recipient of Care

RECIPIENT	Assess		Share Information	Make Decisions	Plan	Deliver			Confirm
	Timely	Beneficial				Safe	Timely	Beneficial	
Patient									
Family									

Settings of Care

CARE SETTING	Patient/Family Centered	Safe	Beneficial	Timely	Efficient
Hospital acute care					
Chronic care facility					
Hospice inpatient					
Nursing home					
Office/clinic					
Home					

Structural and Programmatic Elements of Care

ELEMENTS OF CARE	Patient/Family Centered	Safe	Beneficial	Timely	Efficient
Interdisciplinary teams					
Models of delivery					
Bereavement programs					
Educational programs (professional and volunteer)					
Patient and family education					
Volunteers					
Quality assessment/performance improvement					
Community outreach programs					
Administrative policies					
Information technology and data gathering					
Resolving ethical dilemmas					
Self-care initiatives					

Interdisciplinary Services

SERVICES	Assess		Share Information	Make Decisions	Plan	Deliver			Confirm
	Timely	Beneficial				Safe	Timely	Beneficial	
Primary care physician									
Palliative care specialist physician or advanced practice nurse (APN)									
Nurse									
Pharmacist									
Social worker									
Spiritual care counselor									
Dietician									
Physical/occupational therapist									
Home attendant or home health aide									
Volunteers									

Models of Care Delivery

CARE MODEL	Patient/Family Centered	Safe	Beneficial	Timely	Efficient
Inpatient					
Consultation team					
Outpatient					
Home care					
Residential living					
Combination					

Domains of Care

DOMAIN	Patient/Family Centered	Safe	Beneficial	Timely	Efficient
Structures					
Processes					
Physical					
Psychological					
Social					
Spiritual					
Cultural					
Dying patient					
Ethical and legal					

Acknowledgments

NQF greatly appreciates the support provided for this project by the Robert Wood Johnson Foundation and the Department of Veterans Affairs.

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NATIONAL QUALITY FORUM

Chapter 2 Preferred Practices

Introduction

Over the past three decades, barriers and facilitators to the provision of optimal palliative and hospice care have been studied, developed, and identified. Although palliative and hospice care programs ultimately serve the unique demands of their local communities, a set of preferred practices can serve as the building blocks for high-quality programs across many practice settings and as the basis for developing performance measures. Such practices also reflect the commonality of needs in the populations served by palliative and hospice care professionals and the emerging science about how to best meet those needs.

The NQF-endorsed™ preferred practices derive from the eight domains of quality palliative and hospice care specified within the framework outlined in chapter 1. These practices reflect the multifaceted dimensions comprising today's comprehensive palliative care and hospice care programs; they are based on published studies or widely accepted experiential information and encompass both structural elements and processes of care.

Thirty-eight preferred practices are endorsed as practices that are suitable for implementation by palliative care and hospice programs. Table 1 (at the end of this chapter) presents the preferred practices in the context of the NQF-endorsed aims for healthcare quality; the aim of equitable care is a cross-cutting aim that applies to each cell in table 1.

DOMAIN 1.1. STRUCTURES OF CARE

To provide patients and their families care that addresses their multifaceted needs, palliative and hospice programs should establish the organizational components that will ensure that the provision of this complex care can be achieved. These structural elements provide the foundation that enables the program to achieve its aims.

The Problem

Despite the complex physical, psychological, spiritual, and social needs of palliative care patients, services frequently exclude individuals with expertise in these areas or do not foster communication among experts. Patients who are not treated by an interdisciplinary palliative or hospice care team often receive inappropriate episodic care in acute care settings, resulting in costly care that does not address the totality of the physical, psychological, and spiritual needs of terminally ill patients.^{1,2,3} Studies indicate that the needs of seriously ill patients and their families are not adequately met when managed through routine outpatient office visits or nursing home stays, where care can be fragmented or deficient in critical areas.^{4,5,6,7,8}

PREFERRED PRACTICE 1: Interdisciplinary Teams

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 healthcare professional(s).

Rationale

Using an interdisciplinary team approach is essential to managing the complex needs of patients with serious illness and the needs of their families.⁹ Consultation by an interdisciplinary palliative care team across a spectrum of physicians, nurses, spiritual care counselors, counselors, and social workers effectively reduces symptoms of dyspnea and anxiety and improves sleep quality and spiritual well-being.¹⁰ Using an interdisciplinary team also decreases the number of acute care and physician office visits and improves patient-perceived health status.¹¹ Although more empirical research is needed to

demonstrate how the interdisciplinary team improves patient outcomes,¹² research and professional organizations such as the National Hospice and Palliative Care Organization (NHPCO)¹³ recommend them, as does the National Consensus Project for Quality Palliative Care (NCP).¹⁴

The Problem

Given the continual needs of patients with life-threatening or debilitating illness or injury, it is not possible to manage their care effectively without the reliable, 24-hour availability of palliative or hospice healthcare professionals.²

PREFERRED PRACTICE 2:

Access to Care 24 Hours a Day, 7 Days a Week

Provide access to palliative and hospice care that is responsive to the patient and family 24 hours a day, 7 days a week.

Rationale

Ensuring the availability of palliative and hospice care 24 hours a day, 7 days a week is a minimum standard supported by NHPCO's *Standards of Practice for Hospice Programs*¹³ and NCP's *Clinical Practice Guidelines for Quality Palliative Care* (NCP Guidelines).¹⁴

The Problem

The demand for healthcare services to accommodate the special needs of the elderly, including those with chronic disease, failing health, and terminal illness, is rising as the population in the United States ages. To meet this demand, healthcare professionals are required who are educated in palliative and hospice care and who are appropriately trained to

provide care for the aging and terminally ill population.¹⁵

PREFERRED PRACTICE 3: Continuing Education

Provide continuing education to all healthcare professionals on the domains of palliative care and hospice care.

PREFERRED PRACTICE 4:

Staff Training and Clinical Support

Provide adequate training and clinical support to assure that professional staff are confident in their ability to provide palliative care for patients.

PREFERRED PRACTICE 5:

Staff Training and Credentialing

Hospice care and specialized palliative care professionals should be appropriately trained, credentialed, and/or certified in their area of expertise.

Rationale

There is broad consensus that U.S. clinical education and training fails to adequately provide physicians, nurses, pharmacists, social workers, and mental health workers with essential knowledge and skills in palliative care.¹⁶ Consequently, professional knowledge of palliative care is weak, as reflected in studies showing inadequate treatment of pain and other symptoms in terminally ill patients,^{17,18,19,20} a high incidence of physician referrals to hospice occurring very near the time of a patient's death,²¹ and evidence that physicians seldom initiate discussions with their patients about the goals of care, advance care planning, and treatment preference for end-of-life care.²² Education on the domains of palliative care that is integrated into the

curricula of all basic healthcare professional education programs and provided in continuing education programs would bridge the educational gap for practicing healthcare professionals.²³ This would ensure better pain and symptom management and more timely hospice and palliative care referrals. Offering continuing education that is relevant to staff responsibilities is a standard for NHPCO programs.^{3,24}

DOMAIN 1.2. PROCESSES OF CARE

Providing high-quality palliative and hospice family-centered care requires the institution of formal processes that often transcend the requirements of routine medical practice. Implementing such processes permits the proactive management of the symptom and end-of-life needs of patients cared for by these programs.

The Problem

Patients cite various sources of discomfort during life-threatening or debilitating illness or injury at the end of life, including pain, physical disintegration, and extreme fatigue, as well as feelings related to dependence (fear of being a burden) and a sense of a lack of meaning in life.^{25,26} Appropriate treatment of pain and other symptoms is multifactorial,²⁷ involving symptom assessment, biological markers, imaging technology, observed behaviors and functioning, and patient perceptions.²⁸ Reported patient survey data across primary care systems reveal widespread deficiencies in communication received by patients concerning their care, including providers' failure to answer questions, to make goals clear, or to involve patients in treatment decisions.²⁹

PREFERRED PRACTICE 6: Comprehensive Interdisciplinary Assessment

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.

Rationale

Studies demonstrate that conducting comprehensive interdisciplinary assessments facilitates treatment, identifies overlooked and unreported symptoms, enhances patient and family satisfaction, and leads to improved outcomes in symptom distress and spiritual well-being.^{10,30,31}

The Problem

Coordination of care has been identified by NQF as an area of the highest priority for healthcare quality reporting and measurement³² and has emerged as a significant element in the provision of optimal care for complex, chronic diseases such as cancer.³³ Follow-up of families of patients who have died demonstrate that 15 to 21 percent of these families believe there were significant problems with the coordination of care.^{7,34} Physicians recognize that lack of coordination of care is an organizational barrier to providing effective palliative care.³⁵ Coordination of care is especially apt to be deficient for vulnerable and minority populations.³⁶

PREFERRED PRACTICE 7: Transfer Between Healthcare Settings

Ensure that upon transfer between healthcare 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.

Rationale

Programs in palliative care that are designed to foster coordination of care have been shown to improve outcomes such as patient and family satisfaction, reduced mortality, and decreased use of hospital services, physician office visits, and nursing home admissions.³¹ A systematic review of the impact of coordinated interdisciplinary teams confirms an increase in inpatient and family satisfaction³⁷ compared to care delivered in a conventional manner. A Department of Veterans Affairs demonstration project that includes intensive nurse care coordination has demonstrated high rates of advance planning, hospice enrollment, and death at home and low end-of-life hospital and intensive care use.³⁸ Intensive case management fostering coordination of care has been shown to lead to better outcomes in patients with debilitating chronic illnesses, such as chronic obstructive pulmonary disease and congestive heart failure.³⁹

The Problem

In order for patients to qualify for Medicare coverage of hospice benefits, the attending physician must certify* that the patient's life expectancy is determined to be no more than six months.[†] However, prognostic uncertainty, particularly in diseases other than cancer,⁴⁰ often influences physicians' decisions to delay referral of patients to hospice.^{21,41} The median time that individuals are admitted to hospice is 22 days before death,^{42,43} and survey data show that most family and staff expected the death of the patient to occur prior to its occurrence, an indication that patients could be referred to hospice sooner.²¹

* The first certification is for 90 days. The first recertification also is for 90 days, and all subsequent recertifications are for 60 days (Title 42 CFR section 418.21, as amended).

† See www.hospicenet.org/html/medicare.html.

PREFERRED PRACTICE 8: Presenting Hospice as an Option

Healthcare professionals should present hospice as an option to all patients and families when death within a year would not be surprising and should reintroduce the hospice option as the patient declines.

Rationale

Rates of hospice referral, as well as family satisfaction with care, can increase through the use of simple communication interventions.⁴⁴ Studies have shown that early discussion with patients and families about hospice and early referral to hospice results in improved symptom control, reduction in hospital costs, increased likelihood that a patient will die at home, and a higher level of patient and family satisfaction.^{45,46} The National Comprehensive Care Network *Clinical Practice Guidelines in Oncology* suggest that the initiation of discussion with patients about hospice should occur when a patient's estimated life expectancy is one year or less.⁴⁷

The Problem

Despite generally favorable attitudes toward hospice,^{48,49} many physicians and health professionals do not discuss hospice options until late in the course of a disease, if at all.⁵⁰ Thus, studies have shown that 32.2 percent of family caregivers say hospice was not discussed as an option by their physician,⁵¹ and social workers refer only 49 percent of patients to hospice.⁵² Various impediments to frank and open discussion exist, including communication barriers, such as patient and family unwillingness to consider terminating active treatment and physician difficulty with discussing terminality; structural barriers, such as fear that referral to hospice will be perceived as a way to cut costs;⁵³ and clinical difficulties in recognizing patient survival.⁵⁴ Male physicians and younger physicians have more difficulty than other physicians discussing hospice as an option.⁵⁵

Preferred Practices 9, 10, and 11 relate to the provision of patient-centered services to the patient and family. A critical element in implementing these services is the quality assessment of the manner in which they were presented and the extent to which these educational and shared decisionmaking activities met the recipients' needs. As part of the "Quality of Cancer Care Performance Measures" project, NQF endorsed

the National Hospice and Palliative Care Organization survey instrument, Family Evaluation of Hospice Care (FEHC), which provides an instrument for directly evaluating these services (See box A, below, and appendix E).

PREFERRED PRACTICE 9: Assessment of Physician/Healthcare Professional Presenting Hospice

Patients and caregivers should be asked by palliative and hospice care programs to assess physicians'/healthcare professionals' ability to discuss hospice as an option.

Rationale

The enhancement of communication skills has become a major emphasis in improving patient-physician/health professional relationships, especially when dealing with bad news and end-of-life care.⁵⁶ By assessing patient and family satisfaction with hospice discussions, programs will be able to give feedback to their providers and, when indicated, initiate quality improvement interventions. Education in Palliative and End-of-Life Care (The EPEC™ Project) has developed modules specifically addressing issues such as communicating

Box A – Family Evaluation of Hospice Care

The FEHC was developed at Brown Universityⁱ and adapted by the National Hospice and Palliative Care Organization (NHPCO)ⁱⁱ for use as a hospice-related survey instrument. It was endorsed as a voluntary consensus standard by the NQF Board of Directors in October 2006. This survey instrument contains 61 items and covers the following domains:

- symptom management;
- provision of information about symptoms;
- informing and communicating about the deceased patient;
- attention to family needs; and
- coordination of care.

The survey is administered to the family members of deceased patients who were enrolled in a hospice at the time of their death. No proxies are allowed to respond for a family member. Respondents must be 18 years or older. Family is defined broadly to include anyone who is significant to the patient and involved to some extent in his or her care.

Hospices are instructed to contact family members from one to three months after the death of the patient. Surveys are usually mailed to the families, completed by paper and pencil, and returned to the hospice or a third-party data vendor. Hospices that wish to administer the survey by telephone may do so. Mode testing has demonstrated equivalent results for mail and telephone administration of the survey. The survey is administered as a stand-alone survey or combined with hospice-specific questions. NHPCO discourages adding questions, but if hospice-specific questions are used, the FEHC survey questions must appear first and in the specified order. See appendix E for additional recommendations of the "Quality of Cancer Care Performance Measures" project.

ⁱ Teno JM, Clarridge B, Casey V, et al., Validation of ToolKit After-Death Bereaved Family Member Interview, *J Pain Symptom Manage*, 2001;22(3):752-758.

ⁱⁱ Connor SR, Teno J, Spence C, et al., Family evaluation of hospice care: results from voluntary submission of data via website, *J Pain Symptom Manage*, 2005;30(1):9-17.

“bad news,” negotiating goals of care, dealing with medical futility, and resolving conflict.⁵⁷ Structured programs aimed at medical students and residents also are being developed that could be adapted for more general use.^{58,59,60} The periodic survey of patients and families at the end of life will further enhance the role the receiver of care plays in determining healthcare quality.⁶¹

The Problem

Most Americans want clear and accurate information about their disease,⁶² yet studies suggest that clinicians fail to elicit patients’ concerns, including their values, care goals, and treatment preferences.⁶³ In addition, physicians can over- or underestimate the prognosis^{64,65} or choose not to disclose prognostic information, leaving patients ill-equipped to make important care decisions.

PREFERRED PRACTICE 10: Informed Decisionmaking

Enable patients to make informed decisions about their care by educating them about the process of their disease, prognosis, and the benefits and burdens of potential interventions.

Rationale

Informed decisionmaking occurs only if patients are informed about treatment choices, including the advantages and disadvantages associated with each choice as it relates to probable outcomes.⁶⁷ Informed decisionmaking is facilitated by clinicians who use relational and communications skills^{68,69,70} to provide adequate information to patients and families from the time of the diagnosis of a life-limiting illness through the end of life.⁷¹

The Problem

Surveys of family members and caregivers show that caregivers experience tremendous physical, emotional, and financial stress when caring for a loved one.^{72,73,74} Survey data also reveal that healthcare professionals do not share enough information with caregivers regarding how best to manage their family member’s care or educate caregivers so that they feel confident that they are providing the best possible care.^{74,75,76}

PREFERRED PRACTICE 11: Education and Support

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.

Rationale

Several studies demonstrate that providing educational interventions and support to caregivers improves caregiver knowledge and proficiency in the physical aspects of patient care.⁷⁴ Providing support for caregivers alleviates the burden of illness for patients, families, and clinicians.⁷⁷

DOMAIN 2. PHYSICAL ASPECTS OF CARE

The amelioration of physical symptoms such as pain, fatigue, and nausea and vomiting is an essential component of the improvement of quality of life for palliative care and hospice patients.

The Problem

Multiple studies document poor symptom management across care settings and diseases.^{10,78,79,80,81} Although guidelines recommend the assessment and measurement

of the presence and degree of symptoms in order to ensure safe and effective symptom management, valid measurement instruments are not widely used.^{63,82,83,84,85,86,81}

PREFERRED PRACTICE 12:
Symptom Measurement and Documentation

Measure and document pain, dyspnea, constipation, and other symptoms using available standardized scales.

PREFERRED PRACTICE 13: Symptom Management

Assess and manage symptoms and side effects in a timely, safe, and effective manner to a level that is acceptable to the patient and family.

Rationale

Numerous studies recommend frequent assessment of symptoms using standardized and validated instruments as an essential approach to ensuring safe, timely, and effective pain and symptom management.^{82,83,84,85,86,23} Instruments using standardized scales provide a means for assessing a patient's health status in terms of comfort, symptoms, and function.^{28,82,83,84,85,86,87} Shared decisionmaking among patients, their families, and providers when managing chronic symptoms has been shown to improve health outcomes.^{88,89,90} Management of symptoms and side effects should be in keeping with the patient's overall condition, the level and stability of pain, and specific patient and family wishes.⁹¹

DOMAIN 3. PSYCHOLOGICAL AND PSYCHIATRIC ASPECTS OF CARE

The presence of physical symptoms or entry into the end-of-life phase of an illness evokes a variety of emotional responses that must be dealt with if quality of life is to be preserved. This care ranges from providing emotional support appropriate for all patients to providing specific management of psychological disorders.

The Problem

Despite the prevalence of depression among the elderly and patients with chronic illness or disease,^{92,93,94} psychological symptoms often are undetected by healthcare professionals.^{93,95,96,97}

PREFERRED PRACTICE 14: Psychological Assessment

Measure[‡] and document anxiety, depression, delirium, behavioral disturbances, and other common psychological symptoms using available standardized scales.

PREFERRED PRACTICE 15: Psychological Management

Manage anxiety, depression, delirium, behavioral disturbances, and other common psychological symptoms in a timely, safe, and effective manner to a level that is acceptable to the patient and family.

Rationale

Using standardized instruments to assess psychological symptoms facilitates effective symptom management⁹⁸ and treatment of psychological symptoms in the elderly.^{99,100,101,102} Evidence suggests that psychological symptoms of anxiety, depression, and delirium in individuals with concomitant illness or who are at the end of life can be effectively and safely managed.^{103,104} Patient involvement in care and treatment decisions enhances a sense of autonomy that is essential to managing emotions at the end of life.¹⁰⁵

The Problem

All individuals, including patients and their families, experience grief differently and require different approaches to grief management.^{31,106} Some individuals begin to experience grief more intensely prior to the death of a loved one¹⁰⁷ or experience grief for longer periods.^{106,108} An individual's bereavement period can be prolonged if not correctly assessed and appropriately managed.^{108,109}

[‡] Measurement in this context includes both screening and assessment with standardized scales.

PREFERRED PRACTICE 16:
Reaction to Serious Life-Threatening Illness

Assess and manage the psychological reactions of patients and families (including stress, anticipatory grief, and coping) in a regular, ongoing fashion in order to address emotional and functional impairment and loss.

PREFERRED PRACTICE 17:
Grief and Bereavement Care Plan

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.

Rationale

Ongoing bereavement assessment is considered essential to the appropriate management of grief-induced emotional distress.^{108,110} A bereavement care plan that begins with a grief assessment prior to the point of death is considered the most effective way to plan interventions and prevent individuals from experiencing a more stressful and lengthy grief.^{108,111}

Evidence to establish a specific timeframe for which individuals require bereavement support is lacking. The period of time for which an individual requires bereavement support depends on the individual and his or her relationship with the deceased.¹⁰⁸ A minimum period of 13 months of bereavement support is the NHPCO standard.¹¹²

DOMAIN 4. SOCIAL ASPECTS OF CARE

The impact of disabling symptoms and entry into the terminal phase of an illness has important ramifications on all aspects of family life, ranging from child care to work conditions to financial coping. The palliative care team and hospice must be able to assess these problems and provide resources or make the appropriate referrals to alleviate these burdens.

The Problem

Poor communication among healthcare professionals and patients and families undermines patient and family decision-making and the capacity to effectively manage a patient's life-threatening or debilitating illness or injury.^{23,113}

PREFERRED PRACTICE 18: Care Conference

Conduct regular patient and family care conferences with physicians and other appropriate members of the interdisciplinary team to provide information, to discuss goals of care, disease prognosis, and advance care planning, and to offer support.

PREFERRED PRACTICE 19: Social Care Plan

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, decisionmaking, work and school settings, finances, sexuality/intimacy, caregiver availability/stress, and access to medicines and equipment.

Rationale

Regular consultation with patients and their caregivers by an interdisciplinary palliative care team has proved effective in improving health services utilization and outcomes, such as quality of life, dyspnea, anxiety, and spiritual well-being.¹⁰ Accepted standards of hospice and palliative care are based upon the use of a comprehensive care plan that includes physical, psychological, social, and spiritual well-being and advance care planning.^{13,14}

DOMAIN 5. SPIRITUAL, RELIGIOUS, AND EXISTENTIAL ASPECTS OF CARE

Under the stressful conditions of the palliative care setting, the patient's and family's concerns about religious and spiritual matters become of paramount importance. Programs must be able to assess these needs and provide appropriate resources to meet them.

The Problem

Spirituality is an important, yet often neglected, factor in the health of hospitalized patients.^{114,115} Up to 77 percent of patients would like spiritual issues considered as part of their medical care,¹¹⁶ yet only 10 to 20 percent of physicians discuss these issues with their patients.^{116,117} Other studies indicate that although nurses also have frequent interactions with patients receiving palliative or hospice care, they often do not discuss spirituality with them.^{118,119}

PREFERRED PRACTICE 20: Spiritual Assessment

Develop and document a plan based on an assessment of religious, spiritual, and existential concerns using a structured instrument, and integrate the information obtained from the assessment into the palliative care plan.

Rationale

The NHPCO Standards Committee has developed guidelines for hospice programs, and according to these standards, spiritual concerns are to be addressed during the patient assessment.¹¹²

PREFERRED PRACTICE 21: Spiritual Care Services

Provide information about the availability of spiritual care services, and make spiritual care available either through organizational spiritual care counseling or through the patient's own clergy relationships.

Rationale

Medicare regulations for hospice programs require a spiritual care counselor or other counselor on the interdisciplinary team.¹²⁰ Additionally, the NHPCO Standards Committee has developed guidelines for hospice programs that state that clergy are to be part of, or at least available to, the interdisciplinary teams.¹¹²

PREFERRED PRACTICE 22: Spiritual Training and Certification

Specialized palliative and hospice care teams should include spiritual care professionals appropriately trained and certified in palliative care.

Rationale

Specialized spiritual care often involves understanding and helping with specific theological beliefs and conflicts. It is ideally performed by persons with special training in this area, such as those trained as Clinical Pastoral Education chaplains.^{121,122,123}

PREFERRED PRACTICE 23: Community Partnerships

Specialized palliative and hospice spiritual care professionals should build partnerships with community clergy and provide education and counseling related to end-of-life care.

Rationale

Some patients prefer to use the local spiritual care counseling services of the religious entity to which they belong, however, local religious figures often do not have the appropriate training necessary for counseling palliative care patients and their families. The idea that spiritual care professionals with specialized skills in palliative care should serve as a community resource to local religious institutions is considered to be a “whole community” approach to end-of-life care that encourages communities to provide end-of-life information and support for patients and their families through religious congregations and educational programs.^{122,124} This approach is recommended by the Institute of Medicine.²³

DOMAIN 6. CULTURAL ASPECTS OF CARE

Patient and family reactions to symptoms and entry into the last stages of life are conditioned in part by their cultural beliefs and values. Palliative care and hospice programs must be able to recognize these diverse approaches and tailor interventions to accommodate them.

The Problem

Cultural factors strongly influence patients’ views about serious illness and decisions about end-of-life care. Research has identified three basic dimensions within end-of-life treatment that vary culturally: communication of “bad news”; locus of decisionmaking; and attitudes toward advance

directives and end-of-life care. In contrast to the emphasis on “truth telling” in the United States, it is not uncommon for healthcare professionals outside of the United States to conceal serious diagnoses from patients, because disclosure of serious illness could be viewed as disrespectful, impolite, or even harmful to the patient.¹²⁵ Similarly, with regard to decisionmaking, the U.S. emphasis on patient autonomy contrasts with preferences for more family-based, physician-based, or shared physician- and family-based decisionmaking in some cultures. Finally, survey data suggest that lower rates of advance directive completion among patients of specific ethnic backgrounds might reflect distrust of the U.S. healthcare system, current healthcare disparities, or differing cultural perspectives on death and suffering.^{126,127}

PREFERRED PRACTICE 24: Cultural Assessment

Incorporate cultural assessment as a component of comprehensive palliative and hospice care assessment, including but not limited to locus of decisionmaking, preferences regarding disclosure of information, truth telling and decisionmaking, 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.

Rationale

Culturally appropriate care is fundamental to patient-centered care. Conducting a cultural assessment engenders patient-centered decisionmaking by offering patients the opportunity to explicitly state their care preferences and by providing healthcare professionals with an approach for eliciting patient and family perspectives about care.¹²⁷

The Problem

When professional interpreters are unavailable, healthcare professionals might need to use family members or bilingual healthcare workers for translation. Family or untrained interpreters can, however, misinterpret medical phrases, censor sensitive or taboo topics, or filter and summarize discussions rather than translate them completely.^{128,129}

PREFERRED PRACTICE 25: Interpreter Services

Provide professional interpreter services and culturally sensitive materials in the patient's and family's preferred language.

Rationale

Translations into appropriate languages can help overcome communication barriers and minimize the need for family members to act as interpreters for patients with palliative care needs.³⁴ Trained medical interpreters can ensure effective, efficient, and reliable communication between providers and patients. Healthcare professionals need to bear in mind that interpreters themselves can influence the content of messages conveyed during translations.¹²⁸

DOMAIN 7. CARE OF THE IMMINENTLY DYING PATIENT

When a patient's death becomes imminent, a host of unique needs – both patient centered and family centered – must be addressed. These unique needs require unique programmatic components to help the patient achieve a “good death.”

The Problem

The diagnosis of a patient's transition to the active dying phase is most appropriate when there is agreement among the members of the interdisciplinary team that the patient is likely to die. If the team members are in disagreement, mixed messages and opposing goals of care could be conveyed, leading to poor communication and poor care management.¹³⁰ Many end-of-life patients lose trust in their professional healthcare team when their condition worsens and there is no acknowledgment

that death is imminent.¹³⁰ Patients and their families need to be made aware when death is imminent so that they can be better prepared for when the patient enters the active dying phase.

PREFERRED PRACTICE 26: Active Dying Phase

Recognize and document the transition to the active dying phase, and communicate to the patient, family, and staff the expectation of imminent death.

Rationale

Patient and family satisfaction is improved and patients are less likely to lose trust in their doctor when the patient's doctor informs the patient and family when death is imminent.¹³⁰ The NCP Guidelines recommend recognizing, documenting, and communicating the transition to the active dying phase to the patient, family, and staff. This is also supported by the National Comprehensive Care Network Practice Guidelines in Oncology, which state that if the patient is thought by the team to be in the dying phase (i.e., having only hours or days to live), then this should be communicated to the patient, if appropriate, and to his or her relatives.⁴⁷

The Problem

A large majority of patients and close family members are interested in discussing end-of-life issues with their interdisciplinary team. Many end-of-life discussions do not go beyond the narrow focus of resuscitation. The Family Evaluation of Hospice Care survey found that 28.6 percent of hospices received an unfavorable response regarding their ability to attend to family needs for information about the condition of patients and what to expect.¹³¹

**PREFERRED PRACTICE 27:
Signs and Symptoms of Approaching Death**

Educate the family on a timely basis regarding the signs and symptoms of imminent death in an age-appropriate, developmentally appropriate, and culturally appropriate manner.

Rationale

Providing education on the signs and symptoms of imminent death can help bring relief to families when a patient has reached the active dying phase. Research suggests that such discussions should address the broad array of concerns shared by most dying patients and families: fears about dying, understanding the prognosis, achieving important end-of-life goals, and attending to physical needs.¹³² Good communication can facilitate the development of a comprehensive treatment plan that is medically sound and concordant with the patient's wishes and values. NHPCO standards recommend that family members be educated about the physical and psychological aspects of the dying process. Studies also indicate that families' questions about uncomfortable symptoms should be answered candidly.¹³³

The Problem

In 2003, an estimated 950,000 patients were served by hospice programs.⁴² Even though an NHPCO study found that only 5.5 percent of hospice patients who did not want to be hospitalized were hospitalized at the end of life—despite documentation in their file that they preferred to die at home—more needs to be done to ensure that those who want to die at home can.¹³⁴ Although in the general population, most people die

in the hospital or in a nursing home, surveys indicate that more than 70 percent of people would prefer to die at home.¹³⁵

**PREFERRED PRACTICE 28:
Patient and Family Preferences**

As part of the ongoing care planning process, routinely ascertain and document patient and family wishes about the care setting for the site of death, and fulfill patient and family preferences when possible.

Rationale

The NCP Guidelines recommend that patient and family wishes regarding the care setting for death are documented. Also, the NCP Guidelines recommend that any inability to meet these needs and preferences should be reviewed and addressed by the palliative care team.

The Problem

Pain at the end-of-life is usually treatable, but most dying patients are undertreated and die in unnecessary pain.¹³⁶ Members of the interdisciplinary team must overcome their own fears about using narcotics and addiction and alleviate similar fears in patients, families, and communities.¹³⁶

**PREFERRED PRACTICE 29:
Analgesics and Sedatives at the End of Life**

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.

Rationale

The assessment and management of pain is crucial to the success of any program of care for dying patients and their families. Effective analgesics should be chosen carefully, in keeping with the patient's overall condition, level and stability of pain, and specific patient and family wishes.⁹¹ Ideally, analgesics should be initiated as soon as appropriate. With appropriate assessment and management, often using home health or hospice teams, pain can be controlled in more than 90 percent of patients.¹³⁸

The Problem

Many patients and families are not consulted on their preference of care for the body immediately after death.

PREFERRED PRACTICE 30: Postdeath Preferences

Treat the body after death with respect according to the cultural and religious practices of the family and in accordance with local law.

Rationale

Sensitivity to the patient's cultural and religious background is essential. Formal religious traditions should be observed in the dying phase and should govern care of the body after death.¹³⁰

The Problem

Following death, some families do not receive adequate bereavement support. A major deficiency reported by Department of Health and Human Services surveyors of the hospice industry is that many hospices do not include a plan of care for bereavement services.¹³⁹

PREFERRED PRACTICE 31: Postdeath Bereavement Care Plan

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.

Rationale

After the death of the patient the family becomes the focus of care for the hospice or palliative care team. Effective grieving

is facilitated when families experience good symptom management of the patient during the dying process and when there is opportunity for family, religious, and cultural traditions or rituals to be venerated. Healthcare professionals should conduct appropriate assessments to determine the risk of family members experiencing negative outcomes in bereavement (particularly after the death of a spouse, a child, or a parent of a child).^{140,141,142} Those assessed to be at high risk for negative outcomes benefit most from professional intervention.¹⁴³ Those assessed to be at low risk are more likely to benefit if intervention is directed to their “natural” support systems.^{143,144} The bereavement plan should offer interventions to affected family members based on level of risk.

DOMAIN 8. ETHICAL AND LEGAL ASPECTS OF CARE

To ensure that all patient and family rights are protected and preserved, systematic processes and procedures must be implemented and disseminated.

The Problem

End-of-life care is often not consistent with patients’ preferences. When a patient has lost the capacity or competence to participate in medical decisionmaking and there is no legal documentation that the patient has designated a surrogate to make decisions on his or her behalf, decisionmaking by healthcare practitioners or a state-appointed surrogate can be problematic and result in care decisions that are not consistent with the patient’s preferences.¹⁴⁵

PREFERRED PRACTICE 32: Surrogate/Decisionmaker Designation

Document the designated surrogate/decisionmaker in accordance with state law for every patient in primary, acute, and long-term care and in palliative and hospice care.

Rationale

Patients value having a trusted surrogate to represent them when they can no longer represent themselves.¹⁴⁶ Documentation of a legal surrogate designated by a patient in conformance with state law prevents delayed decision-making and can prevent undesirable care decisions.¹⁴⁵

The Problem

While advance directives provide a mechanism for conveying patient preferences for treatment when a patient is incapacitated, it is impossible to include all possible future treatment options in an advance directive.¹⁴⁶ When a patient's condition progresses, the healthcare options available for the patient might change, requiring new decisions from the patient or surrogate. Unexpected changes in a patient's condition and the plan of care can lead to delayed decisionmaking or to practitioners having to make care decisions that are inconsistent with the patient's/surrogate's wishes. Surrogates and physicians are frequently unaware of patients' preferences with respect to all situations, and advance directives might not include the specificity needed to ensure consistency between preferences and interventions.¹⁴⁷

PREFERRED PRACTICE 33: Patient/Surrogate Preferences

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.

Rationale

Advance directives should not be viewed as a substitute for care planning, which should involve the documentation of an initial assessment and should include frequent discussions between the patient/surrogate and healthcare practitioners regarding the patient's goals for care.¹⁴⁸ Regular interaction and documentation of the patient's care goals serve to better guide decisionmaking that is consistent

with the patient's preferences¹⁴⁹ and increase the likelihood that the patient will die in his or her place of choice.¹⁵⁰

The Problem

Concordance with advance care planning is often problematic. In some instances, the wishes expressed by an advance directive might not be honored due to the unavailability of completed forms or a healthcare professional's inability to quickly translate the language of the document into orders for the treatment of specific medical conditions. As a result, healthcare professionals might initiate or withhold treatments that are medically not indicated or contrary to the desires of the patient.¹⁵¹

PREFERRED PRACTICE 34: Medical Orders

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 hospital care, through a program such as the Physician Orders for Life-Sustaining Treatment (POLST) program.

Rationale

The POLST program is a goal-based approach to advance care planning used by Oregon that has improved the effectiveness of advance care planning and decreased unwanted hospitalizations across the state.¹⁵² Compared with other advance directive programs, POLST more accurately conveys end-of-life preferences and yields higher adherence by medical professionals.^{153,154,155} Other states are replicating this goal-based paradigm,

including its approach to ensuring communication across the healthcare system and system responsiveness.¹⁵⁶ POLST and similar forms are designed to help healthcare professionals honor the treatment goals of their patients and ensure that physician orders are universal and transferable across care settings.¹⁵¹

The Problem

Patients often transfer to different settings during the course of their illness, but administrative systems are not always sufficient to transfer advance care plans to those different settings.

PREFERRED PRACTICE 35: Advance Directives

Make advance directives and surrogacy designations available across care settings, while protecting patient privacy and adherence to Health Insurance Portability and Accountability Act (HIPAA) of 1996 regulations, for example, by using Internet-based registries or electronic personal health records.

Rationale

With the adoption of electronic health record systems, larger health delivery systems have been implementing processes to make advance directives electronically available.^{157,158} Personal health records, controlled by patients rather than providers, are emerging as another way to make advance directives readily available in a mobile society.¹⁵⁸

The Problem

Long after the 1991 passage of the Patient Self-Determination Act, the nation's advance directive completion rate has not

significantly increased, hospice remains underutilized, and patients continue to suffer needlessly at the end of life.¹⁵⁹ Many organizations have limited their focus to developing advance directive materials or documents. Research suggests that the need for a more comprehensive, systematic approach that would encompass a system of training, practices, and policies is needed so that effective advance care planning and end-of-life decisionmaking becomes the routine throughout a health organization or a community.¹⁶⁰

PREFERRED PRACTICE 36:

Advance Care Planning Promotion

Develop healthcare and community collaborations to promote advance care planning and the completion of advance directives for all individuals, for example, the Respecting Choices and Community Conversations on Compassionate Care programs.

Rationale

Collaborative community education efforts have proven successful at improving advance directive completion rates, hospice utilization, and hospice length of stay.¹⁶¹ Additionally, community-wide advance care planning programs can facilitate cultural preferences for family-centered decisionmaking over autonomous approaches.¹⁶² Wisconsin's Respecting Choices program, for example, serves as a successful model for community-based advance care planning that emphasizes collaboration, communication, and trust.^{163,164,165,166}

The Problem

A formal process and expert guidance are needed to resolve complex ethical dilemmas and conflicting views regarding end-of-life decisions.

PREFERRED PRACTICE 37: Ethics Committees

Establish or have access to ethics committees or ethics consultation across care settings to address ethical conflicts at the end of life.

Rationale

An ethics committee is a valuable resource for resolving problems of miscommunication and conflicting values among staff and between staff and patients and families.¹⁶⁷ Ethics consultation is encouraged by the courts¹⁶⁸ and is supported by the President's Commission for the Study of Ethical Problems in Medicine and Biomedical and Behavioral Research¹⁶⁹ and by the requirements of the Joint Commission on Accreditation of Healthcare Organizations.¹⁷⁰

The Problem

Ethical and legal issues can arise from the fact that many terminally ill minors (under 18 years of age) lack ordinary legal authority to make binding medical decisions (including discontinuation of their treatment), yet they meet functional criteria for having the competence to do so.¹⁷¹

PREFERRED PRACTICE 38: Decisionmaking of Minors

For minors with decisionmaking capacity, document the child's views and preferences for medical care, including assent for treatment, and give them appropriate weight in decisionmaking. Make appropriate professional staff members available to both the child and the adult decisionmaker for consultation and intervention when the child's wishes differ from those of the adult decisionmaker.

Rationale

Research suggests that all decisionmaking for children should be collaborative among patients, parents, and professionals.^{171,172} The NCP Guidelines recommend that for minors with decisionmaking capacity, the child's views and preferences for medical care, including assent for treatment, should be documented and given appropriate weight in decisionmaking. Having appropriate staff available to assist families when intrafamily differences exist regarding decisionmaking is based on the key principle that others should be available to facilitate family communication, as advocated by the American Academy of Pediatrics.¹⁷³

Table 1 – Preferred Practices for Palliative and Hospice Care and NQF Aims

PREFERRED PRACTICES		NQF AIMS				
		SAFE	PATIENT CENTERED	BENEFICIAL	EFFICIENT	TIMELY
Domain 1.1: Structures of Care						
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 healthcare professional(s).	•		•		•
2	Provide access to palliative and hospice care that is responsive to the patient and family 24 hours a day, 7 days a week.		•	•	•	•
3	Provide continuing education to all healthcare professionals on the domains of palliative care and hospice care.	•		•		
4	Provide adequate training and clinical support to assure that professional staff are confident in their ability to provide palliative care for patients.	•		•		
5	Hospice care and specialized palliative care professionals should be appropriately trained, credentialed, and/or certified in their area of expertise.	•		•		
Domain 1.2: Processes of Care						
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.		•	•		
7	Ensure that upon transfer between healthcare 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.	•	•	•	•	•
8	Healthcare professionals should present hospice as an option to all patients and families when death within a year would not be surprising and should reintroduce the hospice option as the patient declines.	•	•	•	•	•

Table 1 – Preferred Practices for Palliative and Hospice Care and NQF Aims (continued)

PREFERRED PRACTICES		NQF AIMS				
		SAFE	PATIENT CENTERED	BENEFICIAL	EFFICIENT	TIMELY
Domain 1.2: Processes of Care (continued)						
9	Patients and caregivers should be asked by palliative and hospice care programs to assess physicians'/healthcare professionals' ability to discuss hospice as an option.		•			
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.		•	•		
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.	•		•		
Domain 2: Physical Aspects of Care						
12	Measure and document pain, dyspnea, constipation, and other symptoms using available standardized scales.		•	•	•	•
13	Assess and manage symptoms and side effects in a timely, safe, and effective manner to a level that is acceptable to the patient and family.	•	•	•		•
Domain 3: Psychological and Psychiatric Aspects of Care						
14	Measure and document anxiety, depression, delirium, behavioral disturbances, and other common psychological symptoms using available standardized scales.		•	•	•	•
15	Manage anxiety, depression, delirium, behavioral disturbances, and other common psychological symptoms in a timely, safe, and effective manner to a level that is acceptable to the patient and family.	•	•	•		•
16	Assess and manage the psychological reactions of patients and families (including stress, anticipatory grief, and coping) in a regular, ongoing fashion in order to address emotional and functional impairment and loss.	•	•	•		•

Table 1 – Preferred Practices for Palliative and Hospice Care and NQF Aims (continued)

PREFERRED PRACTICES		NQF AIMS				
		SAFE	PATIENT CENTERED	BENEFICIAL	EFFICIENT	TIMELY
Domain 3: Psychological and Psychiatric Aspects of Care (continued)						
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.		•	•		•
Domain 4: Social Aspects of Care						
18	Conduct regular patient and family care conferences with physicians and other appropriate members of the interdisciplinary team to provide information, to discuss goals of care, disease prognosis, and advance care planning, and to offer support.	•	•	•	•	•
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.		•	•	•	
Domain 5: Spiritual, Religious, and Existential Aspects of Care						
20	Develop and document a plan based on an assessment of religious, spiritual, and existential concerns using a structured instrument, and integrate the information obtained from the assessment into the palliative care plan.		•	•		
21	Provide information about the availability of spiritual care services, and make spiritual care available either through organizational spiritual care counseling or through the patient's own clergy relationships.		•	•		
22	Specialized palliative and hospice care teams should include spiritual care professionals appropriately trained and certified in palliative care.	•		•		

Table 1 – Preferred Practices for Palliative and Hospice Care and NQF Aims (continued)

PREFERRED PRACTICES	NQF AIMS					
	SAFE	PATIENT CENTERED	BENEFICIAL	EFFICIENT	TIMELY	
Domain 5: Spiritual, Religious, and Existential Aspects of Care (continued)						
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.		•	•	•	
Domain 6: Cultural Aspects of Care						
24	Incorporate cultural assessment as a component of comprehensive palliative and hospice care assessment, including but not limited to locus of decisionmaking, 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.		•	•		
25	Provide professional interpreter services and culturally sensitive materials in the patient's and family's preferred language.	•	•	•	•	•
Domain 7: Care of the Imminently Dying Patient						
26	Recognize and document the transition to the active dying phase, and communicate to the patient, family, and staff the expectation of imminent death.		•	•		•
27	Educate the family on a timely basis regarding the signs and symptoms of imminent death in an age-appropriate, developmentally appropriate, and culturally appropriate manner.	•		•		
28	As part of the ongoing care planning process, routinely ascertain and document patient and family wishes about the care setting for the site of death, and fulfill patient and family preferences when possible.		•	•		•
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.	•	•	•		•

Table 1 – Preferred Practices for Palliative and Hospice Care and NQF Aims (continued)

PREFERRED PRACTICES		NQF AIMS				
		SAFE	PATIENT CENTERED	BENEFICIAL	EFFICIENT	TIMELY
Domain 7: Care of the Imminently Dying Patient (continued)						
30	Treat the body after death with respect according to the cultural and religious practices of the family and in accordance with local law.		•	•		
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.		•	•		•
Domain 8: Ethical and Legal Aspects of Care						
32	Document the designated surrogate/ decisionmaker in accordance with state law for every patient in primary, acute, and long-term care and in palliative and hospice care.	•	•	•	•	•
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.		•	•	•	•
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 hospital care, through a program such as the Physician Orders for Life-Sustaining Treatment (POLST) program.	•	•	•	•	•
35	Make advance directives and surrogacy designations available across care settings, while protecting patient privacy and adherence to HIPAA regulations, for example, by using Internet-based registries or electronic personal health records.	•	•	•	•	•
36	Develop healthcare and community collaborations to promote advance care planning and the completion of advance directives for all individuals, for example, the Respecting Choices and Community Conversations on Compassionate Care programs.		•	•		•

Table 1 – Preferred Practices for Palliative and Hospice Care and NQF Aims (continued)

PREFERRED PRACTICES	NQF AIMS					
	SAFE	PATIENT CENTERED	BENEFICIAL	EFFICIENT	TIMELY	
Domain 8: Ethical and Legal Aspects of Care (continued)						
37	Establish or have access to ethics committees or ethics consultation across care settings to address ethical conflicts at the end of life.	•	•	•	•	•
38	For minors with decisionmaking capacity, document the child's views and preferences for medical care, including assent for treatment, and give them appropriate weight in decisionmaking. Make appropriate professional staff members available to both the child and the adult decisionmaker for consultation and intervention when the child's wishes differ from those of the adult decisionmaker.	•	•	•	•	•

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NATIONAL QUALITY FORUM

Chapter 3 Recommendations for Research

Introduction

During the course of this project, gaps in the knowledge base underlying some areas of the framework for palliative and hospice care quality measurement were identified. A significant number of recent reviews also have identified key research needs that would inform palliative and hospice care quality improvement efforts.^{1,2,3} This chapter presents recommendations for high-priority research issues for each of the eight endorsed framework domains, followed by a section on cross-domain research needs.

Structures of Care

For this domain, recommendations are made for additional research to identify innovative arrangements for delivering, coordinating, and evaluating care, including the use of interdisciplinary care teams and quality improvement strategies,³ and for research to evaluate the interaction between outpatient, acute inpatient, and long-term care venues in the overall care of patients with advanced illness. There also should be a focus on identifying facilitators and barriers to coordination of care and consistency of treatment goals within existing structures, as well as on characterizing the implications of alternative conceptual and operational definitions of the end of life, particularly for important conditions. Efforts are needed to define populations with specific symptoms, informational and caregiver needs, and risks of discontinuity.¹

Further recommendations are made for additional research on the evaluation of structures of care across the range of care settings and on organizations that are involved with children who may die, or who have died, and their families (e.g., emergency first-response units, emergency departments, intensive care units, other inpatient units, hospices, home health agencies, and medical examiner offices).³

New modes of care need to be promoted—for example, a diagnosis-independent “care management” approach to palliative care, and there is a need to focus research on methodologies to identify preferred practices. In addition, short lengths of stay (LOS) in hospice require investigation to determine the ideal LOS in hospice, whether there is a relationship between LOS and quality of hospice care, the barriers to and solutions for timely referrals to hospice, and preferred practices that contribute to timely referrals.

Other priority areas for future research include the evaluation of workforce limitations and the availability and recruitment of interdisciplinary teams of skilled professionals in providing palliative and hospice care in rural areas and the evaluation of the role of benefit limits and other reimbursement structures (e.g., pharmacy benefits management policies) that restrict palliative care. An overall assessment of the financial impact of palliative care would help provide needed knowledge, as would the identification of the impact of alternate models for financing healthcare (e.g., globally budgeted systems, provider capitation, fee for service) on care delivery near the end of life. There should be an evaluation of the impact of models that expand hospice financing to permit patients to receive life-prolonging therapies concomitantly with hospice care.

Additional research recommendations for this domain include the need to identify effective and efficient modifications of the current reimbursement system, so as to increase access to palliative and hospice care and to identify optimal methods for determining eligibility for hospice.

Processes of Care

Within this domain, a number of research recommendations are offered, including exploring processes of identifying and meeting the needs of infants, children, and adolescents using developmentally appropriate care strategies³; expanding research on meeting the palliative care needs of other underserved and vulnerable populations (long-term care residents, prison inmates, rural residents, and people living with HIV/AIDS) and the implications for modifying and reorganizing the delivery of palliative and hospice care services; and testing the highest quality measures in important settings (e.g., hospital, nursing home, hospice, home care, ambulatory care) and among diverse populations (e.g., racial/ethnic groups, non-cancer conditions).¹

Other research recommendations include investigating the impact of patient transfers across settings at the end of life and effects on life closure and patient/family goals; evaluating satisfaction measures that reflect specific processes of care and examining the relationship of satisfaction to less-studied processes, such as non-pain symptoms, spiritual support, and continuity;¹ analyzing the roles and relationships of different healthcare professionals and other personnel who are involved with children who may die, or who have died, and their families;³ and determining the learning methods for physicians, other healthcare professionals, and the public in order to help them prepare for their roles in palliative care.

The importance of exploring methods of improving prognostication by physicians and communicating prognoses to patients and families is emphasized, as is examining the prognostication of death and physician education/communication regarding prognosis/life expectancy. Research also is needed that would involve surveying children and families about their specific experiences with care (preferably concurrent with care rather than after the child's death) – not just their global assessments of satisfaction with care³ – and analyzing reasons for delays in the acceptance of hospice and palliative care services, especially as related to pediatric care.

Finally, for this domain research is needed to evaluate novel approaches to improving underutilization and late referrals to hospice; to assess consumer needs and preferences across all domains of care; and to design and implement consumer evaluation methods (e.g., a consumer “report card” for end-of-life care).

Physical Aspects of Care

For the domain of physical aspects of care, recommendations focus on identifying and validating methods for assessing symptoms and other palliative care needs across diverse healthcare settings and initiating the following:

- high-quality studies of the incidence and epidemiology of pain and other symptoms, the relationship among symptoms, and the clinical significance of symptoms in non-cancer conditions;¹

- studies on the best methods for achieving quality improvement in pain management; and
- larger studies of interventions to alleviate dyspnea in cancer and non-cancer conditions,¹ including determining the influence of morphine on the pathophysiology of dyspnea² and evaluating the effectiveness of various opioids for relieving dyspnea including the evaluation of nebulized opioids.²

Furthermore, a broad spectrum of pain management studies should be launched in the areas of analgesia that would include the following:

- improving techniques for drug delivery;²
- evaluating non-steroidal anti-inflammatory drugs;²
- introducing more refined, receptor-specific opioids;²
- identifying novel analgesics that influence non-opioid systems in the central nervous system;²
- identifying accurate easement of patient physical distress;
- strengthening developmental pharmacology intended to maximize benefits and minimize harms by taking into account patient differences in age, race, gender, weight, metabolic status, and other relevant factors;²
- identifying prognostic factors to help guide preventive strategies and linking symptoms to quality-of-life measures to help guide care priorities;²
- improving knowledge of the clinical features and treatment of pain arising in the viscera;² and
- identifying the linkage between pain management and length of stay.

A broad research program on fatigue and cachexia-anorexia-asthenia syndrome should be initiated, including the identification of more precise descriptive terminology for the cachexia-anorexia-asthenia complex and the formation of working groups to create a “common language” for research studies.² Such a program also should include the development of a standard symptom assessment format for studies on fatigue and cachexia-anorexia-asthenia, similar to what is available for pain,² an assessment of the costs of cachexia-anorexia-asthenia complex,² and an investigation of particular therapy options based on a deeper understanding of pathophysiology and the experience of symptoms as reported by patients and families.²

Other research recommendations include the evaluation of clinical interventions for symptom management in children³ and of the cardiovascular, pulmonary, and central nervous system effects of opioids in non-cancer disease, because there is a special need for research in non-malignant disease, given the aging of the population (40 percent of Medicare deaths are due to cardiovascular disease; the number of deaths is expected to double between 2000 and 2030).

Additional research projects that should be undertaken are to identify how aging impacts common symptoms in palliative care (e.g., pain, dyspnea, delirium, constipation); identify the appropriate role for invasive treatment modalities (e.g., surgery, interventional pain management) in

palliative care patients; evaluate the impact of federal, state, or institutional policies regarding opioid prescription on the relief of pain and other symptoms; and evaluate the role of complementary and alternative approaches in symptom relief (e.g., guided imagery, relaxation therapy, massage) in patients with advanced disease.

Psychological and Psychiatric Aspects of Care

For this domain, recommendations focus on the design and implementation of studies that evaluate the short- and long-term treatment of depression in palliative care settings¹ and on the development of studies to evaluate the effectiveness of interventions for dementia caregiving in non-cancer populations, keeping in mind that these studies need to pay special attention to methodologic issues such as the careful, specific measurement of outcome variables.¹

Also noted is the need to initiate a broad range of studies of cognitive and emotional symptoms, which would include the following:

- developing and implementing uniform descriptive terminology and classification schemes where they exist, and developing such terminology and taxonomies of disorders where they do not exist;²
- developing, using, and refining reliable, valid, and practical symptom assessment tools and measures for studying the prevalence and severity of psychological symptoms;² and
- determining the prevalence of neuropsychiatric symptoms and syndromes in patients with different diseases and circumstances and the distress created by these symptoms as reported by patients and families, including:²
 - determining the relative contributions to diminished mental functioning and patient well-being of specific disease processes and the side effects of therapeutic interventions used to treat a disease or relieve some of its symptoms,²
 - analyzing the biochemical, immunological, neurobiological, and other physiological effects of the stresses imposed on patients and those close to them by life-threatening and debilitating diseases and injuries,²

- assessing the costs of different neuropsychiatric syndromes and symptoms as they affect patients with advanced disease,² and
- comparing alternative pharmacological and non-pharmacological therapy options (singly and in combination), including novel uses or combinations of existing therapies.²

Additional research recommendations for this domain involve the need to survey family caregivers' experiences and psychological support needs in illness and bereavement and to examine family dynamics in the care process concerning the treatment of life-threatening and debilitating diseases and injuries. It also would be valuable to compare different approaches to bereavement care³ and determine the psychological effects on professionals of caring for children who die and the consequences for their ability to care for children and parents.³

Standardized measurements of pain and suffering, especially for use with people with cognitive disabilities or dementia, young children, and those who are otherwise non-verbal/non-communicative, are needed. It also would be important to examine bereavement care for the families of patients cared for by non-hospice and palliative medicine teams in the generalist sector and to develop and validate measurement strategies for mental health in patients who are close to death.

Social Aspects of Care

The recommendations for the domain of social aspects of care include those made to analyze the economic and social dimensions of caregiving,¹ to evaluate and test interventions to improve continuity between home and hospital and other settings in which most patients receive care—for example, ambulatory care—and, in addition, to initiate studies to evaluate nursing home-hospital continuity and to design studies that incorporate multiple settings and providers.¹

Furthermore, studies of continuity of care for congestive heart failure should be extended to incorporate the palliative

domains (e.g., physical and psychological symptoms, caregiver burden, advance care planning), and evaluation is needed regarding whether these interventions are generalizable to the sickest patients and patients with multiple comorbidities.¹ The healthcare experiences of children and families outside the healthcare system also require analysis, including an enhanced focus on schools as a critical element in pediatrics.³

An evaluation of the effects of uncertainty in diagnosis, prognosis, and treatment on communication with children and families, the establishment of care goals and care plans, decisions about interventions, preparation for death, and family perspectives and emotions after death would be important,³ as would be a survey of the needs of parents, siblings, and other family members throughout serious illness and extending into bereavement.³

Communication research should be extended to include aspects of listening skills and patient/provider team/family/communication, and there is a need to evaluate institutional, regional, or state policies addressing medical futility – that is, persistent disagreement between providers and caregivers about life-sustaining treatments.

Other research recommendations for this domain include the development of the means of assessing quality of life in the setting of palliative care that are sensitive to change over time and the identification of the role of informal caregiving networks in end-of-life care for patients who do not have family caregivers.

Spiritual, Religious, and Existential Aspects of Care

In this area, research recommendations are made to evaluate methods for assessing spiritual and religious needs and interventions for the existential aspects of end-of-life care as well as to extend research in “spiritual care” beyond religious issues to understand all aspects of spirituality and the interaction of culture and spirituality. There also is a need to develop better metrics for the transcendent dimension of the spiritual experience of dying patients and to measure outcomes regarding the impact of interventions of faith-based communities and religious denominations on the quality of the end-of-life experiences of patients and families.

Cultural Aspects of Care

Research recommendations for cultural aspects of care include those involving the exploration of culture, communication, perceptions, and decisionmaking,^{1,3} including provider bias and stereotyping that may surface under duress and when structural issues arise.

Other recommendations focus on the need to evaluate the impact of culturally based rituals on illness, death, funeral/burial, and bereavement and to identify the unmet end-of-life needs of racial, ethnic, and cultural minority populations and the implications of these unmet needs for the modification and reorganization of the delivery of hospice and palliative care services.

Care of the Imminently Dying Patient

Recommendations in this area include developing interventions to enhance the education and support provided to families near the time of death; identifying the special needs of pediatric patients and their families when death is imminent; identifying factors contributing to the successful communication about end-of-life issues; and evaluating the value of “End of Life Protocols” in the care of the imminently dying patient.

Ethical and Legal Aspects of Care

The initiation of a rigorous research program on advance care planning is needed in order to understand how to best achieve patient and family goals (as opposed to evaluating resource allocation) and to address the fundamental processes of care planning.¹ Other research recommendations include the development of methods and processes for improving communication and preventing or resolving conflicts among clinicians, patients, and family members³ and the clarification of ethical and practical issues related to conducting clinical research in patients who are near the end of life.

Topics That Cross Domains

In the area of cross-domain topics, the recommendations are to develop performance measures around palliative and hospice care; to strengthen the research infrastructure, including collaborative networks, in order to facilitate the study of

methodological challenges in measurement that require focused research¹; to launch studies regarding the epidemiology of death and dying¹; and to evaluate the delivery, financing, and improvement of healthcare and other services.¹

There also is a need to evaluate the efficiency of palliative and hospice care services; to analyze the range of causes and trajectories of death, including sudden, unexpected deaths, deaths from progressive chronic conditions, and deaths from conditions diagnosed prenatally³; and to determine the most effective vehicles for disseminating end-of-life care quality information to consumers, including:

- identifying which quality measures are most appropriate and useful;
- determining which messages and formats are most effective in delivering the information; and
- analyzing which roles end-of-life care and referring providers can play in the dissemination of information.

Other cross-domain recommendations include the following:

- derive and validate models for predicting survival in serious, chronic conditions;
- implement a palliative care research consortium to facilitate multi-institutional collaborative palliative care research;
- evaluate the role of rapid technological advances in disease management on decisionmaking and the delivery of palliative care;
- evaluate palliative care teams’ approaches to self-care and the impact of self-care strategies on provider outcomes (e.g., job satisfaction, mental health, burnout);

- address the needs of unique populations that lack decisionmaking capacity, such as the unrepresented elderly, intellectually disabled individuals, and children;
- develop methodologies for conducting clinical trials that are specific to the special vulnerabilities and needs faced by palliative care patients; and
- develop strategies and data collection methods that permit multi-institutional research while assuring the adequate protection of patient privacy.

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Appendix A

Members and Board of Directors

Members*

CONSUMER COUNCIL

AARP
 AFL-CIO
 AFT Healthcare
 American Hospice Foundation
 Childbirth Connection
 Consumers Advancing Patient Safety
 Consumers' Checkbook
 Consumer Coalition for Quality Health Care
 International Association of Machinists
 March of Dimes
 National Breast Cancer Coalition
 National Citizens' Coalition for Nursing Home Reform
 National Coalition for Cancer Survivorship
 National Family Caregivers Association
 National Partnership for Women and Families
 Service Employees International Union
 State of California - Office of the Patient Advocate

HEALTH PROFESSIONAL, PROVIDER, AND HEALTH PLAN COUNCIL

Administrators for the Professions
 Adventist HealthCare
 Advocate Health Partners
 Aetna
 Alegen Health
 Alexian Brothers Medical Center
 Alliance for Quality Nursing Home Care
 American Academy of Family Physicians

American Academy of Ophthalmology
 American Academy of Orthopaedic Surgeons
 American Academy of Pediatrics
 American Association of Nurse Anesthetists
 American Clinical Laboratory Association
 American College of Cardiology
 American College of Chest Physicians
 American College of Emergency Physicians
 American College of Gastroenterology
 American College of Obstetricians and Gynecologists
 American College of Physicians
 American College of Radiology
 American College of Rheumatology
 American College of Surgeons
 American Geriatrics Society
 American Heart Association
 American Hospital Association
 American Managed Behavioral Healthcare Association
 American Medical Association
 American Medical Group Association
 American Nurses Association
 American Optometric Association
 American Osteopathic Association
 American Society for Gastrointestinal Endoscopy
 American Society for Therapeutic Radiology and Oncology
 American Society of Anesthesiologists
 American Society of Clinical Oncology
 American Society of Health-System Pharmacists

*When voting under the NQF Consensus Development Process occurred for this report.

American Society of Interventional Pain Physicians
American Society of Plastic Surgeons
America's Health Insurance Plans
Ascension Health
Association of Professors of Medicine
Atlantic Health System
Aurora Health Care
Baptist Memorial Health Care
Bayhealth Medical Center
Baylor Health Care System
Beverly Enterprises
BJC HealthCare
Blue Cross and Blue Shield Association
Bon Secours Health System
Bronson Healthcare Group
Calgary Health Region - Quality Improvement and Health Information
Catholic Health Association of the United States
Catholic Health Initiatives
Catholic Healthcare Partners
Cedars-Sinai Medical Center
Centura Health
Chesapeake Bay ENT
Child Health Corporation of America
Children's Hospitals and Clinics of Minnesota
CHRISTUS Health
CIGNA Healthcare
Clark Consulting
College of American Pathologists
Connecticut Hospital Association
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Detroit Medical Center
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Evanston Northwestern Healthcare
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Exeter Health Resources
Federation of American Hospitals
First Health
Florida Hospital Medical Center
Gentiva Health Services
Good Samaritan Hospital
Greater New York Hospital Association
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HCA
HealthHelp
Healthcare Leadership Council
Health Management Associates
HealthPartners
The Heart Center of Indiana
Henry Ford Health System
Hoag Hospital
Horizon Blue Cross and Blue Shield of New Jersey
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HRDI
Hudson Health Plan
Illinois Hospital Association
INTEGRIS Health
Intermountain Healthcare
John Muir/Mt. Diablo Health System
Johns Hopkins Health System
Kaiser Permanente
KU Med at the University of Kansas Medical Center
Lake Forest Hospital
Los Angeles County - Department of Health Services
Lutheran Medical Center
Mayo Foundation
Medical University of South Carolina
MedQuest Associates
MedSphere
MedStar Health
Memorial Health University Medical Center
Memorial Hermann Healthcare System
Memorial Sloan-Kettering Cancer Center
Mercy Medical Center
Meridian Health System
The Methodist Hospital
Milliman Care Guidelines
Munson Medical Center
National Association for Home Care & Hospice
National Association of Chain Drug Stores
National Association of Children's Hospitals and Related Institutions
National Association of Public Hospitals and Health Systems
National Consensus Project for Quality Palliative Care
National Consortium of Breast Centers
National Hospice and Palliative Care Organization
National Rural Health Association
Nebraska Heart Hospitals
Nemours Foundation
New York Presbyterian Hospital and Health System
Northwestern Memorial Corporation
North Carolina Baptist Hospital
North Mississippi Medical Center
North Shore-Long Island Jewish Health System
North Texas Specialty Physicians
Norton Healthcare
Novant Health
Oakwood Healthcare System
PacifiCare
PacifiCare Behavioral Health
Palmetto Health Alliance
Park Nicollet Health Services
Partners HealthCare
Premier
Presbyterian Healthcare Services
Providence Health System

Robert Wood Johnson Health Network
 Robert Wood Johnson University Hospital-Hamilton
 Robert Wood Johnson University Hospital-New Brunswick
 Sentara Norfolk General Hospital
 Sisters of Charity of Leavenworth Health System
 Sisters of Mercy Health System
 Society of Critical Care Medicine
 Society of Thoracic Surgeons
 Sodexo Healthcare Services
 St. Mary's Hospital Medical Center
 Stamford Health System
 State Associations of Addiction Services
 State University of New York-College of Optometry
 Sutter Health
 Tampa General Hospital
 Tenet Healthcare
 Thomas Jefferson University Hospital
 Triad Hospitals
 Trinity Health
 UAB Health Systems
 UnitedHealth Group
 University Health Systems of Eastern Carolina
 University Hospitals of Cleveland
 University of California-Davis Medical Group
 University of Michigan Hospitals and Health Centers
 University of Pennsylvania Health System
 University of Texas-MD Anderson Cancer Center
 US Department of Defense-Health Affairs
 UW Health
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 eHealth Initiative
 Eli Lilly and Company
 Florida Initiative for Children's Healthcare Quality
 Forum of End Stage Renal Disease Networks
 GlaxoSmithKline
 Health Alliance of Mid-America
 Health Care Compliance Strategies
 Health Care Excel
 Health Grades
 Health Information Management Systems Society
 Health Resources and Services Administration
 Health Services Advisory Group
 Illinois Department of Public Health
 Infectious Diseases Society of America
 Institute for Clinical Systems Improvement
 Institute for Safe Medication Practices
 Integrated Healthcare Association
 Integrated Resources for the Middlesex Area
 Iowa Foundation for Medical Care
 IPRO
 Jefferson Health System Office of Health Policy and
 Clinical Outcomes
 Johnson & Johnson Health System
 Joint Commission on Accreditation of Healthcare
 Organizations
 Long Term Care Institute
 Loyola University Health System Center for
 Clinical Effectiveness
 Lumetra
 Maine Quality Forum
 McKesson Corporation
 MedAssets
 Medical Review of North Carolina
 MedMined
 Medstat
 Minnesota Community Measurement
 National Academy for State Health Policy
 National Association for Healthcare Quality
 National Committee for Quality Assurance
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 National Patient Safety Foundation
 National Research Corporation
 New York University College of Nursing/John A.
 Hartford Institute
 Northeast Health Care Quality Foundation
 North Carolina Center for Hospital Quality and
 Patient Safety
 Ohio KePRO
 OmniCare
 Online Users for Computer-Assisted Healthcare

Owens & Minor and Hospira
 Partnership for Prevention
 Pennsylvania Health Care Cost Containment Council
 Pennsylvania Patient Safety Authority
 Pfizer
 PhRMA
 Physician Consortium for Performance Improvement
 Press, Ganey Associates
 Professional Research Consultants
 ProHealth Care
 Renal Physicians Association
 Research!America
 Roswell Park Cancer Institute
 sanofi-aventis
 Select Quality Care
 Society for Healthcare Epidemiology of America
 Solucient
 State of New Jersey Department of Health and
 Senior Services
 Substance Abuse and Mental Health Services
 Administration
 Texas Medical Institute of Technology
 Uniform Data System for Medical Rehabilitation
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 Outcomes
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¹ Chair through December 2005; Chair Emeritus since January 2006

² Appointed to the Board of Directors and named Chair-Elect in May 2005; became Chair in January 2006

³ Through September 2005

⁴ Since March 2006

⁵ Through December 2005

⁶ February 2005 through August 2005

⁷ NQF President and CEO since February 2006; also was Liaison Member representing the Institute of Medicine through May 2005

⁸ Since March 2006

⁹ Through December 2004

¹⁰ Through February 2005

¹¹ Through January 2005

¹² Since February 2006

¹³ NQF President and CEO through November 2005

¹⁴ Since August 2006

¹⁵ Since February 2006

¹⁶ Through October 2006

¹⁷ Since March 2006

¹⁸ Through October 2006

¹⁹ Since January 2005

²⁰ October 2005 to August 2006

²¹ Through October 2005

²² Since January 2005

²³ Since October 2005

²⁴ Through December 2005

²⁵ Since August 2005

²⁶ October 2005 to June 2006

²⁷ Since April 2006

NATIONAL QUALITY FORUM

Appendix B

Review Committee and Project Staff

Review Committee

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Cornell Center
New York, NY

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Authority
Olympia, WA

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AseraCare
Humble, TX

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Lumetra
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Philadelphia, PA

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Minneapolis, MN

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Robyn Y. Nishimi, PhD

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Vice President, Operations

Rodger Winn, MD

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Program Director

Del M. Conyers, MPH

Research Analyst

Ellen T. Kurtzman, RN, MPH

Senior Program Director

Lisa J. McGonigal, MD

Contractor

Sara Davidson Maddox

Contractor

¹ Since February 2006

² Through November 2005

³ Through March 2006

NATIONAL QUALITY FORUM

Appendix C Commentary

As with other projects, this National Quality Forum (NQF) project involved the active participation of a Review Committee* composed of representatives from across the spectrum of healthcare stakeholders (appendix B), particularly in the areas of palliative and hospice care. This appendix summarizes the deliberations of the Review Committee and its recommendations for the palliative and hospice framework, for a minimum set of preferred practices, and for future research.

Background

The Review Committee was asked to provide input in three ways:

- recommend a national consensus framework for discussing and evaluating palliative care across all health settings and professions, utilizing the National Consensus Project for Quality Palliative Care's (NCP's) *Clinical Practice Guidelines for Quality Palliative Care* (NCP Guidelines)^{†,1} as the starting point for discussion;
- recommend a minimum set of preferred practices for palliative care for national consensus based on the framework; and
- provide guidance on identifying performance measures that comport with the recommended framework and preferred practices.

* Because the NQF Board of Directors approved this project for expedited consensus, a "Call for Frameworks and Practices" was not performed. Rather, the National Consensus Project for Quality Palliative Care's *Clinical Practice Guidelines for Quality Palliative Care* (2004) was used as the starting point. Under expedited consensus, the Committee is referred to as a Review (not Steering) Committee.

† The NCP Guidelines were derived by the American Academy of Hospice and Palliative Medicine, the Center to Advance Palliative Care, the Hospice and Palliative Nurses Association, the Last Acts Partnership, and the National Hospice and Palliative Care Organization.

The NCP Guidelines, which were the result of consensus across five organizations, were compared with the national frameworks of Australia,² Canada,³ Ireland,⁴ New Zealand,⁵ the National Institute of Clinical Excellence (NICE),⁶ and the National Hospice and Palliative Care Organization's (NHPCO's) standards of practice for hospice programs.⁷

Definitions

The Committee recommended the definitions for palliative and hospice care based on the following:

- palliative care begins at the time of diagnosis of a life-threatening or debilitating illness or injury;
- the delivery of palliative care may occur in the setting of the administration of life-prolonging therapy or in a setting where the sole aim is the amelioration of suffering;
- hospice is a delivery system that serves the subset of the palliative care patients who have entered the end-of-life phase of their illness; and
- end-of-life care is a specific phase of palliative care requiring specialized skills and services that may be served by the delivery of hospice care or other models of palliative care programs.

The Committee agreed that palliative care manages a life-threatening or debilitating illness or injury across a continuum of care that includes disease-modifying treatment, palliative care, hospice care, and bereavement support. It also believed that a major aspect of palliative care is the

extension of care to the family during the bereavement phase, and it noted that this aspect of care distinguishes palliative care from other types of medical care, because it focuses on families in addition to patients and extends care beyond the cessation of patient-directed efforts.

A major point that the Committee wanted to convey in its work was that the range of palliative services was not restricted to those related to end-of-life care. Thus, the Committee recommended that palliative care not be defined in terms of prognosis (e.g., terminal illness or life expectancy of six months), but rather in terms of the provision of care and services for the patient and family from the point of diagnosis across a continuum that extends past the patient's death through a family bereavement period.

To make this point clear and to complement the definitions of palliative and hospice care, considerable attention was given to the elements of a continuum-of-care diagram. (See chapter 1.) This diagram emphasizes that the institution of palliative care becomes appropriate at the time of diagnosis and extends through the periods of disease-modifying therapy, terminal illness, and bereavement care. It also indicates the role of both hospice and palliative care in the terminal phases of the disease trajectory. Of note, the Committee explicitly rejected defining the beginning of hospice care in terms of when hospice services are covered by the Medicare Hospice Benefit (i.e., six months before death), or any other reimbursement qualifications. Instead, the view is that hospice care becomes appropriate as the terminal phase begins, but it

also indicates that the patient may still be undergoing disease-modifying therapy at the time that hospice services are instituted.

Purpose

The Committee recognized the importance of recommending a framework that is consistent with other NQF project frameworks—that is, it should serve as a conceptual model of the principles and categories that direct the derivation of a quality measurement and reporting system. Additionally, the Committee noted that it also should guide the development of detailed measure elements in a consistent and coherent manner. To establish the purpose of the framework, the Review Committee recommended that:

- the framework address palliative and hospice care as it currently exists and not in terms of how the delivery of care might develop in the future;
- the elements of the framework provide organizations with an approach to evaluating existing palliative care services and a blueprint for identifying gaps and developing new programs; and
- the scope, goals, principles, and preferred practices outlined in the framework should be based on the six NQF-endorsed™ aims of quality care: safe, beneficial, timely, patient centered, efficient, and equitable.

Goals and General Principles

The Committee discussed two approaches for applying the framework. First, the framework should address the philosophy,

principles, and requirements of palliative and hospice care across the continuum of care. Second, the framework should address the organizational structures for delivering that care. Thus, the recommended framework is intended to provide guidance both on what care is to be provided and how it is to be delivered.

During the Committee's deliberations on the goals and principles, several foci of palliative care emerged that distinguished it from other aspects of medical care:

- **Family-centered care.** The Review Committee believed strongly that the unit of care is not the patient alone, but the patient and the family. When planning services, including educational, social, and economic interventions, the needs of the family as well as of the patient should be considered.
- **Interdisciplinary care.** The Review Committee emphasized that, in order to provide the complete spectrum of palliative care services, a team approach is necessary.
- **Specialized education.** The Committee believed that all team members must be specifically trained and educated in the delivery and precepts of palliative care.
- **Advance care planning.** Advance care planning is an important first step to providing access to palliative care, since it ensures that patients' wishes are transferred across care settings, leading to early referrals to hospice and decreases in unwanted hospitalizations at the end of life. The Review Committee thought that assigning the responsibility for promoting advance care planning across all settings, including hospitals, nursing facilities, and home health agencies, was an important goal.

Scope

In its discussions about the scope of palliative and hospice care, the Committee addressed the boundaries that define palliative care and therefore the areas to be included in the framework. The following parameters were considered important in the scope recommended by the Committee:

- The framework and preferred practices apply not only to those events encountered at the end of life but include all aspects of palliative care.
- Palliative care applies to all patients whose clinical condition could lead to a major disruption in function. For example, patients undergoing curative therapy for leukemia may also require palliative care services.
- Each element in the framework should be interpreted as appropriate for both adult and pediatric care, including children who may have congenital injuries or conditions requiring full-life care.
- The provision of palliative care occurs at two levels: 1) as part of the care delivered by healthcare professionals responsible for the routine care of the patient's life-threatening or debilitating illness or injury and 2) as specialized palliative care. The Committee noted that in the first instance, this general palliative care could be delivered by specialists, such as oncologists or neurologists. For the delivery of specialized palliative care, professionals should have specialized training or certification.

Structural and Programmatic Elements

The Committee identified 12 structural and programmatic elements of palliative and hospice care that it believed should be essential components of the recommended framework. For each element, the Committee also recommended additional subcomponents and/or guiding principles fundamental to the element.

Interdisciplinary Teams

The Committee noted that an interdisciplinary team is a key element of how palliative and hospice care are best delivered because the needs of the patient and family are too complex to be served by one professional discipline. Given the specialized skills required to deliver palliative care, the Committee recommended that there ultimately should be certification for all specialties, although it acknowledged that this currently does not exist; thus, the Committee felt that it is essential that specialized training be provided regardless of the setting of care delivery. Additionally, the Committee noted that specialized palliative care training will facilitate coordination of care because it improves knowledge of when the services of interdisciplinary specialist-level palliative healthcare providers are indicated and how to access them.

Models of Delivery

Multiple models of care can be used for delivering palliative care. The models of delivery that the Committee recommended

to be included in the framework were intended only as examples and were not intended to limit the development of new models and innovations. The Committee explicitly recommended that palliative care models should continue to evolve to include any combination of settings that is warranted by the needs of patients and families.

Bereavement Programs

Bereavement programs are offered through hospice or palliative care programs, and the Committee recommended that the framework should include a 13-month bereavement period. The Committee believed that this is a necessary structural and program requirement because, in practice, the first anniversary of the patient's death is especially difficult for families, and offering 13 months of bereavement support includes this critical period.

Educational Programs

The Committee stressed that all members of the interdisciplinary teams require appropriate training, education, and orientation regarding the precepts of palliative care. Educational programs would therefore consist of general topics that apply to the responsibilities of all team members and discipline-specific educational sessions to ensure that each member meets the requirements specific to his or her specialty. It was emphasized that special attention also must be paid to the orientation and training of volunteers.

Patient and Family Education

The Committee emphasized that programs to educate the patient and family regarding the signs and symptoms of approaching death must be presented in an age-appropriate, developmentally appropriate, and culturally appropriate manner.

Volunteers

Although the use of volunteers is an integral part of the Medicare Hospice Benefit, it is not a requirement of palliative care programs. Furthermore, there are clinical situations (e.g., when a patient has been admitted to an intensive care unit) in which volunteers should not be involved in the care of the patient. The Committee recommended that the framework should explicitly note that the use of volunteers is not appropriate across all settings of care.

Quality Assessment/Performance Improvement (QA/PI)

In order to ensure that a palliative care or hospice organization maintains the highest levels of care, formal attention must be paid to QA/PI programs, which must be a delegated organizational responsibility, with a mechanism in place for reports to be made to senior leadership so that remedial actions are supported. A major issue is the appropriation of sufficient resources to make these programs effective.

Community Outreach Programs

Because palliative care and hospice organizations serve their communities, it is vital that they receive feedback from the community. In addition, in order to

promote the use of end-of-life care services, active promotional programs are of inestimable use.

Administrative Policies

The Committee strongly believed that coordination of care and referrals are essential components for a well-functioning and efficient interdisciplinary team. To achieve this, the Committee felt that explicit administrative policies must be developed and broadly disseminated; it did not believe that coordination of care could be achieved by ad hoc, random decisionmaking.

Information Technology and Data Gathering

The science of palliative care has progressed to the point where solid research has provided a substantial number of validated survey tools that enable caregivers to systematically assess the needs of their patients and families. The use of these standardized instruments allows organizations to improve patient care by assessing needs in a consistent manner. It also facilitates the aggregation of data that can then be trended over time to further quality improvement initiatives.

Resolving Ethical Dilemmas

Inherent in the palliative care process is the broaching of ethical issues that may raise conflict because of varying cultural, social, or personal orientations. The resolution of these issues in a fair and sensitive manner is vital to the goal of providing satisfactory care. Given the complexity of these issues,

and because ad hoc, informal processes may lead to inconsistent, untimely, or aggravating solutions, formal mechanisms for resolution must be in place.

Self-Care Initiatives

The stress experienced by palliative care caregivers is real, but often it is not recognized. The training of team members should include methods for recognizing and dealing with stress.

Domains of Palliative and Hospice Care

In formulating its recommendations for the framework, the Committee discussed the overall content of the NCP Guidelines and compared them with other national frameworks^{2,3,4,5,6,7} and the NHPCO standards for hospice care. Based on its deliberations on the strengths and weaknesses of the various frameworks, the Committee recommended a framework built upon the eight domains identified in the NCP report. The Committee thought that these eight domains, which also are delineated in many other frameworks, encompass the essential elements of good palliative care: structures and processes of care; 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.

One organizational difference between the NCP Guidelines' domains and the domains in the NQF framework is that the NQF framework separates structures and

processes of care. The Committee believed that separating these elements would enable future measure development to focus on these specific areas and avoid potential overlap. In addition, the NQF framework consolidates the NCP Guidelines into a shorter, more concise set of guidelines and principles. In deriving the domains for the NQF framework, the Committee recommended including the domains and specific guidelines, as outlined in the NCP Guidelines. Of note, the Committee believed that the criteria stated in the NCP Guidelines delineated possible preferred practices, and therefore it did not recommend their inclusion in the framework. Rather, as described later in this appendix, some of this information has been recommended in the form of preferred practices from which performance measures could be developed.

Levels of Measurement

The NCP Guidelines did not specify a typology for addressing levels of measurement of the healthcare system. In developing a comprehensive quality performance measure set, however, the Committee recommended that palliative care should be evaluated at three levels of the healthcare system, since deficiencies in quality may occur at any of them: the patient-focused level, the organization-focused level, and the system- or community-focused level. The Committee noted that implementing the framework using this three-tiered typology should enable planners to focus on measure sets directed at the specific level of the healthcare

system in which change can be affected. The Committee also recognized that measures might be applicable across levels.

Outcomes

Although the NCP Guidelines do not address outcomes, the Committee stressed that a framework for measurement and reporting should provide guidance for identifying appropriate outcomes. Based on a literature review conducted by NQF staff to identify pertinent sources detailing outcomes in palliative care,^{8,9,10,11,12,13,14,15,16,17} the Committee recommended that outcomes for palliative and hospice care must be derived for the specific indications for which they are used; currently no standard set of outcomes for palliative care exists. Specifically, the Committee noted the following:

- there is no systematic approach to delineating palliative care outcomes;
- the evidence supporting the linkage of interventions to outcomes may be absent or anecdotal; and
- patient-centered outcomes often are intuitively derived.

The Committee considered mapping the framework's domains and preferred practices to four outcome categories identified by NHPCO's National Hospice Workgroup (and included in the proposed rules for Hospice Conditions of Participation¹⁸): comfortable dying; self-determined life closure; safe dying; and effective grieving. Although these outcomes were useful in terms of their application to end-of-life care, the

Committee ultimately recommended against their inclusion because it believed that they did not apply precisely to other aspects of the palliative care continuum.

Preferred Practices

To identify preferred practices, the Review Committee initially considered the NCP Guidelines. Each of the eight domains in the NCP Guidelines contained “criteria” for assessing performance, which in many instances can be characterized as preferred practices, since they represent interventions that have documented efficacy in achieving optimal outcomes. Thus, as an initial step, the Committee used a list of preferred practices drawn from the NCP Guidelines and recommended the most important practices for consideration based on the degree to which each practice impacted the delivery of quality care. Committee members also identified additional preferred practices based on their organizational experiences and knowledge of efficacious interventions in the palliative care and hospice literature. This section summarizes the deliberations that led to the Committee’s recommendations.

PREFERRED PRACTICE 1: Interdisciplinary Teams

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 healthcare professional(s).

The Committee noted that the complex work of palliative care requires a set of interdisciplinary specialists working as a team. The Committee recognized that randomized studies definitively documenting this do not exist, but that the recommendation for an interdisciplinary team is in keeping with the recommendations of the NCP Guidelines and the National Comprehensive Cancer Network guidelines.

In discussing the preferred practice related to interdisciplinary teams, the Committee concluded that preferred practices might pertain to several dimensions of quality care:

- Interdisciplinary teams are an aspect of care at the system (organizational) level and probably are not feasible at the individual practitioner level—for example, individual practitioners do not have dedicated social workers in their offices.
- Care delivered in different settings will determine the staff mix of the interdisciplinary team—for example, discharge planning is not important at the nursing home level.

The Committee noted that while the membership of each interdisciplinary team may differ to meet a patient’s current needs, the core members should include physicians, nurses, and social workers, since all patients’ needs require these services in all settings. The Committee also believed that because spiritual care counselors provide unique services to palliative care/hospice teams, their inclusion in interdisciplinary teams should be given prime consideration.

PREFERRED PRACTICE 2:**Access to Care 24 Hours a Day, 7 Days a Week**

Provide access to palliative and hospice care that is responsive to the patient and family 24 hours a day, 7 days a week.

The Committee agreed that access to palliative care was a major quality issue, because even if the best structure and processes are in place, if the patient has no access to them when they are needed, his or her care would not be optimal. It was noted that some hospital-based palliative care programs, especially start-up palliative programs, offer services during regular business hours only, so that the establishment of a preferred practice for 24-hour-a-day, 7-day-a-week (24/7) access would serve as a stretch goal that could be used in planning resource allocation.

The Committee also noted that while palliative and hospice care services should be responsive to the patient and family on a 24/7 basis, it may not always be feasible to do so in the patient's/family's setting of choice, for example, the home setting. Thus, the practice calls for responsiveness that might include telephone access and referral to an available setting.

PREFERRED PRACTICE 3:**Continuing Education**

Provide continuing education to all healthcare professionals on the domains of palliative care and hospice care.

The Committee noted that because palliative medicine is a relatively new component of medical care and many professionals were not exposed to specialized

training during their formative years, ongoing continued education is needed to introduce the concept of palliative care and teach the necessary skills. In addition, the Committee noted that as new techniques and processes of care emerge, continuing education will be necessary to translate innovative approaches into practice.

PREFERRED PRACTICE 4:**Staff Training and Clinical Support**

Provide adequate training and clinical support to assure that professional staff are confident in their ability to provide palliative care for patients.

The Committee noted that gaps in training exist among palliative care providers and that studies have shown that medical education does not adequately incorporate the principles of palliative care. The Committee emphasized that all professionals in all disciplines providing palliative services need to have the specialized training that will enable them to provide this specialized care. In addition, Committee members stressed that programs must have educational resources available to provide on-the-job training as new or difficult problems arise.

PREFERRED PRACTICE 5:**Staff Training and Credentialing**

Hospice care and specialized palliative care professionals should be appropriately trained, credentialed, and/or certified in their area of expertise.

A major thrust of the Committee's discussion focused on the goal of having

certification available for all professionals providing palliative care. Currently, only programs for physician and nurse certification (for all levels of nursing) exist. The Committee believed that, short of certification, all staff should be trained in their profession (e.g., spiritual care counselors, social workers) as it pertains to palliative and hospice care.

**PREFERRED PRACTICE 6:
Comprehensive Interdisciplinary Assessment**

Formulate, utilize, and regularly review a timely care plan based upon 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.

The Committee noted that a care plan for palliative patients must be comprehensive and interdisciplinary – that is, it should not be fragmented or unidimensional. Conducting a comprehensive interdisciplinary assessment of the patient's and family's values, preferences, and goals is an established standard of practice for hospice programs, but it is not necessarily a standard practice for palliative care programs. Given the documented importance of the care plan, the Committee felt that a comprehensive care plan should be implemented in all palliative care programs and shared across providers and settings as the patient transitions across points of care, including from an acute care setting to a primary care provider.

**PREFERRED PRACTICE 7:
Transfer Between Healthcare Settings**

Ensure that upon transfer between healthcare 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.

Following the Member and public comment period regarding this report, the Committee agreed that a preferred practice should be added to emphasize that care coordination should occur across all settings and that patient information (including goals, preferences, values, and clinical information) needs to be conveyed to all parties as the patient transitions between providers or care settings. The Committee acknowledged that instituting an interdisciplinary care plan does not assure that the information in the care plan is transferred with the patient within a setting or across settings. The Committee therefore wanted to emphasize the importance of conveying patient information within and across settings or providers and the coordination of care within and across entities.

**PREFERRED PRACTICE 8:
Presenting Hospice as an Option**

Healthcare professionals should present hospice as an option to all patients and families when death within a year would not be surprising and should reintroduce the hospice option as the patient declines.

The Committee noted that while studies suggest that referral to hospice leads to improved health outcomes at the

end of life, this option is frequently not offered to patients and families. Data indicate that only 30 percent of patients receive hospice services, despite the availability of these services in more than 95 percent of U.S. counties. Therefore, the Committee suggested that a practice specifically related to hospice referral should be recommended. The Committee discussed at length the matter of when the hospice option should be discussed with the patient and family. The Committee ultimately recommended the specific timeframe, since it believed that an open-ended recommendation would not foster early discussion; the aim was to direct physicians to consider death in the future occurring earlier than they might normally consider it.

The Committee noted that the norm is to present hospice as an option late in the course of life-threatening disease, as evidenced by the overall short length of stay in most hospices; federal Medicare guidelines call for hospice services when life expectancy is six months or less. However, the Committee recommended that hospice should be presented as an option in cases in which death within one year would not be surprising. The Committee felt that this practice would ensure an earlier introduction of hospice, so that the patient and family could be prepared for eventual hospice referral. Committee members also noted that with this timeframe the physician has more flexibility to plan for appropriate services throughout the course of illness. Of note, the Committee believed that having the first discussion with a patient and family about hospice at the time of diagnosis was

too early and not appropriate in some circumstances—for example, upon first diagnosis of congestive heart failure. The recommended timeframe also reflects studies that have demonstrated that physicians tend to be inaccurate in their prognoses; thus, the less clinical phrase “death within a year would not be surprising” was recommended.

**PREFERRED PRACTICE 9:
Assessment of Physician/Healthcare
Professional Presenting Hospice**

Patients and caregivers should be asked by palliative and hospice care programs to assess physicians’/healthcare professionals’ ability to discuss hospice as an option.

NQF consumer Members felt strongly that families and patients should be surveyed to assure that their needs were being met specifically with regard to discussion of hospice. Since this area had not been directly addressed in other preferred practices, a new practice was added to include this outreach activity.

**PREFERRED PRACTICE 10:
Informed Decisionmaking**

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.

The Committee noted that studies have shown that clinicians fail to elicit patients’ concerns, including their values, goals of care, and treatment preferences.

The Committee also noted that physicians often overestimate the prognosis, or choose not to disclose prognostic information, leaving patients ill equipped to make important care decisions.

**PREFERRED PRACTICE 11:
Education and Support**

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.

In addressing the needs of the palliative care patient, especially when in the terminal phase of illness, the needs of the attendant family members and informal caregivers also must be addressed. The Committee noted that studies have shown that providing educational interventions and support to caregivers improves caregiver knowledge and proficiency in the physical aspects of patient care. The Committee also acknowledged that current practice does not provide patients, families, and caregivers with adequate information to make informed decisions about the receipt and/or delivery of care.

**PREFERRED PRACTICE 12:
Symptom Measurement and Documentation**

Measure and document pain, dyspnea, constipation, and other symptoms using available standardized scales.

The Committee noted that symptom-related guidelines facilitate the development of an effective care management plan. Unfortunately the availability of standardized, validated scales is still limited, and

these scales are most broadly applied in the management of pain. Additionally, the Committee concluded that while the assessment and documentation of dyspnea is important because optimal control is achieved with objective assessment, current standardized scales are not widely used. Thus, it specifically recommended including dyspnea in the preferred practice in order to stimulate increased usage. Of note, the Committee also believed that, as standardized scales become more widely available for other symptoms, these and any measures developed from them should be included in the practices.

**PREFERRED PRACTICE 13:
Symptom Management**

Assess and manage symptoms and side effects in a timely, safe, and effective manner to a level that is acceptable to the patient and family.

The Committee noted that studies have shown that pain has been inadequately managed in hospitals, ambulatory care settings, nursing homes, and hospice care. The key issue addressed in this preferred practice is that the acceptable level to which symptoms should be ameliorated must be defined by the patient, rather than by some arbitrary intensity level; one patient might elect to experience a higher level of pain than another in return for being more mentally clear. The Committee further noted that studies have shown that frequent assessment of symptoms is considered an essential approach to ensuring safe, timely, and effective pain and symptom management.

**PREFERRED PRACTICE 14:
Psychological Assessment**

Measure and document anxiety, depression, delirium, behavioral disturbances, and other common psychological symptoms using available standardized scales.

In addressing psychological issues, the Committee considered research that revealed that anxiety, depression, and delirium are the most common problems encountered in managing the palliative care/hospice patient. The Committee noted that studies in the management of depression in the primary care setting and the treatment of psychological symptoms in the elderly have shown that the use of standardized assessment instruments supports effective symptom management.

**PREFERRED PRACTICE 15:
Psychological Management**

Manage anxiety, depression, delirium, behavioral disturbances, and other common psychological symptoms in a timely, safe, and effective manner to a level that is acceptable to the patient and family.

In recommending a practice related to psychological management, the Committee recognized that while the spectrum of psychological symptoms is broad, anxiety, depression, delirium, behavioral disturbances, and dementia are the most prominent symptoms to be addressed. The Committee noted that studies have shown that patient involvement in care and treatment decisions enhances a sense

of autonomy that is essential to managing emotional distress at the end of life.

**PREFERRED PRACTICE 16:
Reaction to Serious Life-Threatening Illness**

Assess and manage the psychological reactions of patients and families (including stress, anticipatory grief, and coping) in a regular, ongoing fashion in order to address emotional and functional impairment and loss.

Patients and families facing a serious life-threatening illness undergo normal psychological reactions, including stress, issues involving coping, and anticipatory grief. Anticipatory grief in patients occurs because of the sense of impending loss and loss of functional status; for families, anticipatory grief results from the realization of the impending death of the patient. The Committee believed that the onset of these distressful reactions must be recognized so that preventive interventions can be initiated. The Committee noted that in addressing issues of grief, stress, and coping, it must be recognized that the patient cannot be supported in isolation—that is, the needs of the family in its entirety must be addressed. The Committee also indicated that for many physicians, management of these psychological reactions might consist of referral to appropriate mental health personnel and that it is incumbent on these practitioners to identify the appropriate professionals for assistance.

**PREFERRED PRACTICE 17:
Grief and Bereavement Care Plan**

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.

The Committee noted that while proposed hospice standards require that bereavement services be provided, there is no such requirement for palliative care programs. For the families of the two-thirds of patients who die outside of a hospice program, only about 5 percent will be offered a bereavement program by their palliative care team or a generalist. Additionally, the Committee strongly recommended that bereavement services should be provided for at least 13 months, realizing that some patients may require a shorter or longer bereavement period; the 13-month period is intended to overlap with the first anniversary of the patient's death.

PREFERRED PRACTICE 18: Care Conference

Conduct regular patient and family care conferences with physicians and other appropriate members of the interdisciplinary team to provide information, to discuss goals of care, disease prognosis, and advance care planning, and to offer support.

The Committee felt that the provision of information and support to patients and families requires a periodic formal conference. The Committee noted that studies have shown that regular consultation to patients and caregivers can improve outcomes and reinforce adherence to prescribed care. It rejected informal

meetings, such as hallway consultations with a physician and one family member, as inadequate to meet patient and family needs. In addition the Committee recommended that meetings and conferences should be applied across all healthcare settings (e.g., intensive care unit, neonatal intensive care unit, private office, emergency department).

The Committee recognized that the coordination of schedules for busy health professionals would present some logistical burdens, but it believed strongly that meetings in a private office should be interdisciplinary, with attendance by local hospice workers or social workers as needed.

In discussing what mix of attendees should constitute a care conference, the Committee felt that the presence of the physician responsible for the patient was essential and that other members of the interdisciplinary team should be included based on the particular clinical, psychological, social, and spiritual needs to be addressed. The physician's presence was considered important so that clinical decisions could be made at the meeting and the care plan could be recommended or revised.

PREFERRED PRACTICE 19: Social Care Plan

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, decisionmaking, work and school settings, finances, sexuality/intimacy, caregiver availability/stress, and access to medicines and equipment.

The Committee emphasized that comprehensive social assessment is new territory for many healthcare professionals and therefore recommended that the major components of a social assessment be included explicitly. The Committee especially wanted to draw attention to the needs of caregivers in addition to those of patients. The Committee also noted that a social assessment plan should address sexuality/intimacy, an area frequently overlooked in social planning.

PREFERRED PRACTICE 20: Spiritual Assessment

Develop and document a plan based on an assessment of religious, spiritual, and existential concerns using a structured instrument, and integrate the information obtained from the assessment into the palliative care plan.

In addressing the area of spirituality, the Committee recommended making the practice as inclusive as possible to encompass issues beyond the realm of religion. The inclusion of “existential concerns” ensures that issues such as life meaning and life review are included. Although the Committee recognized that these issues might become paramount during the time surrounding death, it felt that any life-threatening or severe chronic illness raises spiritual issues that need to be addressed on an ongoing basis.

The Committee recognized that the process of conducting a spiritual assessment can itself serve as an intervention—that is, the act of asking about spiritual matters may be sufficient to meet patient and family needs. The Committee also believed

that although standardized instruments addressing religious, spiritual, and existential concerns are broadly available, many hospitals have developed their own instruments or surveys to meet local needs and that these structured tools were acceptable.

PREFERRED PRACTICE 21: Spiritual Care Services

Provide information about the availability of spiritual care services, and make spiritual care available either through organizational spiritual care counseling or through the patient’s own clergy relationships.

The Committee noted that not all patients and families want to utilize a palliative care program’s pastoral services in place of those in their own religious community. The Committee felt that palliative care programs should have procedures for referring their patients back to the community and providing the local spiritual counselors with the information needed for the ongoing support of patients and families.

PREFERRED PRACTICE 22: Spiritual Training and Certification

Specialized palliative and hospice care teams should include spiritual care professionals appropriately trained and certified in palliative care.

Specialized spiritual care in the palliative care setting often involves helping patients and families come to an understanding about their specific theologic beliefs in the

context of life-threatening illness. Ideally this counseling should be performed by persons with special training, since the standard training of spiritual care professionals may not address such issues. The Committee noted that specialized programs exist—for example, Clinical Pastoral Education programs—to provide interfaith professional education for the ministry. Through these programs, pastoral care professionals develop new awareness of themselves as persons and of the needs of those to whom they minister, and they develop skills in interpersonal and inter-professional relationships.

The Committee recognized that the availability of specialized pastoral training could not realistically be expected to exist in all care settings and therefore recommended that the practice should apply to the specialized palliative care and hospice settings.

PREFERRED PRACTICE 23: Community Partnerships

Specialized palliative and hospice spiritual care professionals should build partnerships with community clergy and provide education and counseling related to end-of-life care.

The Committee noted that because many specialized palliative care and hospice care facilities may not be able to provide spiritual services for all of its patients and families, it is important to build relationships with community clergy who can provide the necessary services. It noted that many community-based spiritual

counselors do not have training in end-of-life care and that palliative care and hospice programs can play a major role in serving as a resource for providing such education.

PREFERRED PRACTICE 24: Cultural Assessment

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.

The Committee noted that studies have shown that cultural background and values may affect a patient's preference of care. Therefore, the Committee felt that healthcare professionals should include an assessment of the specific beliefs and practices of the patients they serve in the initial formulation of a comprehensive care plan and that it is important to recognize that this includes an inquiry regarding whether an individual patient adheres to these cultural beliefs. The Committee noted that several programs have effectively incorporated culturally specific information into brochures in order to provide culturally sensitive information.

PREFERRED PRACTICE 25: Interpreter Services

Provide professional interpreter services and culturally sensitive materials in the patient's and family's preferred language.

The Committee noted that studies have shown that providing professional interpreters ensures reliable communication between providers and patients. The Committee also noted that the difficulty involved in having a family member or non-professional translator (e.g., nurses) serve as an interpreter is that he or she may be inaccurate or introduce his or her own biases.

PREFERRED PRACTICE 26: Active Dying Phase

Recognize and document the transition to the active dying phase, and communicate to the patient, family, and staff the expectation of imminent death.

The Committee acknowledged that the patient, the family, and staff often have difficulty recognizing and accepting the patient's impending death. In identifying the preferred practice, there was discussion of the timeframe of "imminent death," and the Committee recommended that the length of time for imminent death should be measured in days to a few weeks. The Committee believed that documentation in the medical record that a patient has transitioned to the active dying phase and communication with the patient and family of this transition are critical but rarely followed practices in most care settings. The Committee felt these practices to be important for future measure development.

PREFERRED PRACTICE 27: Signs and Symptoms of Approaching Death

Educate the family on a timely basis regarding the signs and symptoms of imminent death in an age-appropriate, developmentally appropriate, and culturally appropriate manner.

Current practices often do not entail the education of patients, families, and staff about the symptoms that accompany the active dying phase. This lack of preparedness may lead to unnecessary hospitalizations. The Committee also noted that educating families about the signs and symptoms of death relieves family members of distress during the dying process.

PREFERRED PRACTICE 28: Patient and Family Preferences

As part of the ongoing care planning process, routinely ascertain and document patient and family wishes about the care setting for the site of death, and fulfill patient and family preferences when possible.

As part of the ongoing care plan, patient preference for site of death should be documented. The Committee felt this was particularly important in the hospital setting so that patients could be returned home if that was their desire. The Committee noted that despite survey data showing the great majority of patients would prefer to die at home, only 20 percent die in their residences. It was also recognized that because preference for site of death may change over time, reassessing the preference in the active dying phase is

extremely important. If it is not possible to fulfill the patient's wishes, the family should be informed of why the patient's wishes were not honored.

**PREFERRED PRACTICE 29:
Analgesics and Sedatives at the End of Life**

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.

The Committee noted that studies have shown that most patients die in unnecessary pain. The Committee wanted to ensure that the end-of-life outcome of comfortable dying was achieved. One important factor in determining whether this goal is met is the provision of adequate dosage of opioids and sedatives in the terminal phase of disease. The Committee noted that many physicians not skilled in palliative care believe that pain medication and sedatives can be reduced or eliminated in the terminal phase. In reality these patients require ongoing medication for sustained comfort. Patient and family preferences, a patient's overall condition, and the level and stability of pain should be considered when providing pain management.

**PREFERRED PRACTICE 30:
Postdeath Preferences**

Treat the body after death with respect according to the cultural and religious practices of the family and in accordance with local law.

A major aspect of a family's social and cultural values relates to the treatment of the body after death. There are distinct differences among the beliefs and values of cultural and religious groups of which the palliative care team should be aware. The Committee felt strongly therefore that the family should be consulted regarding its preference of care for the patient's body immediately after death. This practice reflects the orientation of palliative and hospice care to meet the needs of the family as well as those of the patient.

**PREFERRED PRACTICE 31:
Postdeath Bereavement Care Plan**

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.

Grieving occurs at the point of death, and therefore bereavement support must be provided without delay. The Committee recognized that the development of a bereavement plan would ensure that seamless attention would be paid to the family's needs. Ideally, the bereavement plan would be implemented as close to the moment of the patient's death as feasible.

**PREFERRED PRACTICE 32:
Surrogate/Decisionmaker Designation**

Document the designated surrogate/decisionmaker in accordance with state law for every patient in primary, acute, and long-term care and in palliative and hospice care.

The Committee noted that at the end of life, many patients lose their ability to make well-informed medical decisions. As many as 40 percent of nursing home patients may be cognitively impaired. Naming a surrogate ensures that patients' preferences and values will be respected when they can no longer represent themselves. It is important that this designation be documented in the appropriate medical record or management plan so that the designee can be easily contacted in times of urgent decisionmaking.

**PREFERRED PRACTICE 33:
Patient/Surrogate Preferences**

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.

The Committee noted that advance care planning can clarify appropriate decisionmaking for persons with life-limiting illness, thereby decreasing turmoil, confusion, and anxiety. The difficulties encountered in the Terri Schiavo case brought into focus the need for adequate documentation of preferences and goals. The Committee also noted that patient and family preferences should be assessed

regularly as needs, goals, and conditions change.

PREFERRED PRACTICE 34: Medical Orders

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 hospital care, through a program such as the Physician Orders for Life-Sustaining Treatment (POLST) program.

The Committee noted that effective advance care planning can be achieved only if all healthcare providers across multiple relevant healthcare settings are knowledgeable about the patient's goals and that one of the most significant barriers to achieving this aim is the failure to transmit patient preferences from one setting to another. The Committee felt that the implementation of a system that converted patient preferences into medical orders, such as the POLST program, and that could be transferred by the patient from one medical location to the next would be a significant step in overcoming this obstacle; these formatted orders would be accepted across all community healthcare settings. One of the elements contributing to the success of the POLST program is that it entails community collaboration and cooperation. The Committee felt that models of this program in states such as Oregon were being disseminated broadly and that the goal of nationwide distribution was achievable and would be aided by the endorsement of this preferred practice.

PREFERRED PRACTICE 35: Advance Directives

Make advance directives and surrogacy designations available across care settings, while protecting patient privacy and adherence to Health Insurance Portability and Accountability Act of 1996 regulations, for example, by using Internet-based registries or electronic personal health records.

The Committee recognized that successful implementation of advance care planning requires that it be available across the continuum of care; relying on the transfer of paper documentation across settings is difficult and is therefore often overlooked. The Committee felt that with the development and use of new technological advances that facilitate medical communication and coordination, it is now possible to use these new methods to ensure easy access to a patient's advance care directives across medical settings. Prototype systems such as posting advance directives on a system's electronic network exist, and therefore this preferred practice meets the readiness criteria.

**PREFERRED PRACTICE 36:
Advance Care Planning Promotion**

Develop healthcare and community collaborations to promote advance care planning and the completion of advance directives for all individuals, for example, the Respecting Choices and Community Conversations on Compassionate Care programs.

The Committee noted the need for the institution of structural elements not only at the organizational level, but also at

the community/system level, including working for change through legislation. Recognizing this, the Committee recommended an advocacy role for palliative care and hospice programs that could be used in reaching out to the community to ensure that education is available about the need for advance care planning at the population level.

PREFERRED PRACTICE 37: Ethics Committees

Establish or have access to ethics committees or ethics consultation across care settings in order to address ethical conflicts at the end of life.

When significant ethical dilemmas in patient management arise, formal processes should be in place to address them. Ethics committees ensure that professionals with experience in dealing with complex ethical dilemmas can lend their expertise to help sort out the issues, define the areas of disagreement, and help the parties to arrive at a mutually acceptable resolution of the problem. Recognizing that ad hoc, informal approaches are frequently ineffective in dealing with these difficult problems and may worsen the situation, the Committee recommended that ethics committees should be established across care settings so that they can adjudicate and/or negotiate conflict resolution when there are problems of miscommunication and/or conflicting values.

PREFERRED PRACTICE 38: Decisionmaking of Minors

For minors with decisionmaking capacity, document the child's views and preferences for medical care, including assent for treatment, and give them appropriate weight in decisionmaking. Make appropriate professional staff members available to both the child and the adult decisionmaker for consultation and intervention when the child's wishes differ from those of the adult decisionmaker.

The Committee stressed that all of the principles of good palliative and hospice care are applicable in the pediatric setting. A broad consensus exists that there is an ethical imperative for pediatric patients to collaborate with parents and professionals in the decisionmaking process. The Committee noted that while decisionmaking responsibility may rest with parents, pediatric patients should be involved in the decisionmaking process in a developmentally appropriate manner. It further noted that the inclusion of the young patient in this process may often be facilitated by the guidance of a professional staff member who has experience and training in this area, especially if the child's preferences are at variance with the recommended management plan.

Performance Measures

The Committee recognized that a fundamental purpose of a framework is to provide guidance for identifying and developing appropriate performance measures.

Toward that end, the Committee recommended the following:

- An evaluation of care should capture each phase of the patient-healthcare professional interaction across the care continuum (i.e., assessment, providing patients and families with information, making decisions, planning care, delivering care, and confirming results of care).³
- Access to palliative care specialists is a key consideration when evaluating the performance of the interdisciplinary team.
- A critical component of measuring end-of-life care is the extent to which advance care planning is transmitted from provider to provider and across the settings and levels of care.
- Particular consideration should be given to capturing community-level data related to advance care planning. The Review Committee believed that this is necessary in order to understand the percentage of advance care directives in communities and to analyze and measure where people are dying and where they want to die.

Research Agenda for Palliative and Hospice Care

The Review Committee noted that because neither the framework nor the NCP Guidelines provides supporting empirical evidence for all its recommendations at this point in the development of palliative care, research in a number of areas is needed. The Review Committee was cognizant that, while progress has

been made in the field to delineate outcome measures for assessing the quality of palliative care, the development of quality metrics in end-of-life care is embryonic, and the recommended preferred practices are not intended as the final word, but rather as tools for promoting the improved quality of palliative and hospice care.

Two approaches were used to identify areas for further research: each member of the Review Committee was asked to provide suggestions for research areas, and key research areas were compiled from three source documents^{19,20,21} and organized for inclusion by domain. These were then reviewed by the Committee.

The major areas for further research identified by the Review Committee were as follows:

- the integration of palliative and end-of-life care at the health system level;
- the cardiovascular, pulmonary, and central nervous system effects of opioids in non-cancer disease;
- spiritual, as opposed to religious, insights and modes of care for patients near the end of life; and
- the assessment of consumer needs and preferences in end-of-life care.

The various research topics identified in the literature were matched to the eight framework domains. Included as overarching research areas were research recommendations that crossed more than one domain.

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Appendix D

Consensus Development Process: Summary

The National Quality Forum (NQF), a voluntary consensus standards-setting organization, brings together diverse healthcare stakeholders to endorse performance measures and other standards to improve healthcare quality. Because of its broad stakeholder representation and formal Consensus Development Process (CDP), NQF-endorsed™ products have special legal standing as voluntary consensus standards. The primary participants in the NQF CDP are NQF member organizations, which include:

- consumer and patient groups;
- healthcare purchasers;
- healthcare providers, professionals, and health plans; and
- research and quality improvement organizations.

Any organization interested in healthcare quality measurement and improvement may apply to be a member of NQF. Membership information is available on the NQF web site, www.qualityforum.org.

Members of the public with particular expertise in a given topic also may be invited to participate in the early identification of draft consensus standards, either as technical advisors or as Steering Committee members. In addition, the NQF process explicitly recognizes a role for the general public to comment on proposed consensus standards and to appeal healthcare quality consensus standards endorsed by NQF. Information on NQF projects, including information on NQF meetings open to the public, is posted at www.qualityforum.org.

Each project NQF undertakes is guided by a Steering Committee (or Review Committee) composed of individuals from each of the four critical stakeholder perspectives. With the assistance of NQF staff and

technical advisory panels and with the ongoing input of NQF Members, a Steering Committee conducts an overall assessment of the state of the field in the particular topic area and recommends a set of draft measures, indicators, or practices for review, along with the rationale for proposing them. The proposed consensus standards are distributed for review and comment by NQF Members and non-members.

Following the comment period, a revised product is distributed to NQF Members for voting. The vote need not be unanimous, either within or across all Member Councils, for consensus to be achieved. If a majority of Members within each Council do not vote approval, staff attempts to reconcile differences among Members to maximize agreement, and a second round of voting is conducted. Proposed consensus standards that have undergone this process and that have been

approved by all four Member Councils on the first ballot or by at least two Member Councils after the second round of voting are forwarded to the Board of Directors for consideration. All products must be endorsed by a vote of the NQF Board of Directors.

Affected parties may appeal voluntary consensus standards endorsed by the NQF Board of Directors. Once a set of voluntary consensus standards has been approved, the federal government may utilize it for standardization purposes in accordance with the provisions of the National Technology Transfer and Advancement Act of 1995 (P.L. 104-113) and the Office of Management and Budget Circular A-119. Consensus standards are updated as warranted.

For this report, the NQF CDP, version 1.7, was in effect. The complete process can be found at www.qualityforum.org.

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Appendix E

Quality of Cancer Care Performance Measures: National Voluntary Consensus Standards for Symptom Management and End-of-Life Care in Cancer Patients

In September 2002, the National Quality Forum (NQF) launched a multiyear, two-phase “Quality of Cancer Care Performance Measures” project with the objective of addressing issues of quality care for cancer patients in the United States. Phase 2 of the project was initiated in May 2004 and had as its specific aim the endorsement of cancer-related, evidence-based voluntary consensus standards for public accountability, internal quality improvement (QI) only, and surveillance. The project identified three areas for initial consideration: diagnosis and treatment of breast cancer; diagnosis and treatment of colorectal cancer; and symptom management/end-of-life care in cancer patients. During 2005 and 2006, the Symptom Management and End-of-Life Technical Panel and the Cancer Steering Committee evaluated the submitted measures and made recommendations to the NQF membership.

In October 2006, NQF endorsed nine voluntary consensus standards for assessing symptom management and end-of-life cancer care for patients with cancer:¹

¹National Quality Forum (NQF), *National Voluntary Consensus Standards for Symptom Management and End-of-Life Care in Cancer Patients: A Consensus Report*, Washington, DC: NQF; in press.

Measures-Accountability, QI, and Surveillance

- Family Evaluation of Hospice Care–National Hospice and Palliative Care Organization (NHPCO)

Measures-QI and Surveillance

- Comfortable dying-NHPCO

**Measures-Surveillance
(all Dana Farber Cancer Institute)**

- Chemotherapy in the last 14 days of life
- More than one emergency room visit in the last 30 days of life
- More than one hospitalization in the last 30 days of life
- Intensive care unit admission in the last 30 days of life
- Not admitted to hospice
- Admitted to hospice for less than three days
- Death in an acute care setting

Also endorsed was a recommendation that all of the measures approved for QI and surveillance should be further developed for accountability purposes. An additional measure, Self-Determination of Life Closure (NHPCO), was endorsed for further development.

Given the paucity of measures submitted or otherwise identified in the area of symptom management and end-of-life care for cancer, the report also identifies a comprehensive research agenda that entails establishing a national cancer care quality initiative charged with addressing the basic conceptual and infrastructure issues required to produce a comprehensive, standardized set of quality of cancer care performance measures.

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ISBN 1-933875-06-2



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