NATIONAL QUALITY FORUM

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

A CONSENSUS REPORT

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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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:

[1] National 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.

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.

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

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