

Operational Features for Hospital Palliative Care Programs: Consensus Recommendations

David E. Weissman, M.D. and Diane E. Meier, M.D.

Abstract

Hospital palliative care programs in the United States are growing in number, scope, and sophistication. The nation's major public-private partnership organization charged with advancing the quality of health care, the National Quality Forum (NQF), developed *A Framework for Preferred Practices for Palliative and Hospice Care Quality: A Consensus Report*. This Framework establishes a set of 38 preferred practices associated with quality palliative care. In an effort to provide supportive operational detail about specific features necessary for program sustainability and growth and to help guide hospitals starting new or strengthening existing palliative care programs, the Center to Advance Palliative Care convened a consensus panel to develop recommendations for key operational features for hospital programs. Twenty-two recommendations are grouped into 12 domains and include "must-have" and "should-have" features. The recommendations can be used for strategic planning of new or established hospital-based palliative care programs.

Introduction

THE GROWTH OF HOSPITAL PALLIATIVE CARE PROGRAMS has been rapid in the past 10 years, with just under 1300 hospitals reporting some type of program as of 2006.¹ Although palliative care programs are increasingly recognized as an essential element of comprehensive inpatient medical and surgical services, the process of starting, growing, and sustaining a program so that it is fully embedded in the culture and practice of a hospital is a serious challenge, requiring strong leadership and dedication by key staff and receptive hospital administrators. For almost 10 years, the Center to Advance Palliative Care (CAPC) and its six Palliative Care Leadership CentersSM have provided outreach and technical assistance to hundreds of hospitals during the start and growth of their palliative care programs. Through this experience, the CAPC staff, consultants, and Palliative Care Leadership CenterSM faculty have learned what is helpful to, and what hinders, program development.

The National Quality Forum (NQF)'s, *A Framework for Preferred Practices for Palliative and Hospice Care Quality*, developed in 2006, has been a keystone for helping legitimize palliative care practice and provides a clear set of 38 practices necessary for delivery of quality palliative care (Table 1).² The purpose of this report is to support the NQF preferred practices with a set of specific operational details necessary for sustainable high-quality hospital palliative care programs (hereafter referred to as "programs"). To this end, a consensus

panel of CAPC staff, consultants, and Palliative Care Leadership Center (PCLC)SM faculty was convened in the winter of 2008 to answer the question, "What operational details are essential, for sustainability/growth, for hospital palliative care programs? The panel had interdisciplinary representation from academic and community hospital settings, single hospitals and large health systems, and from programs coordinated by hospice agencies and hospitals (Table 2).

The consensus panel worked over a 3-month period debating operational details, and eventually consolidated recommendations within 12 discrete but complementary domains. Within each domain, one or more recommendations have been made as either a "must-have" or a "should-have" program feature. The panel recognized the wide range of hospital size (some program elements will be more difficult to implement for smaller hospitals) and that larger hospitals have a responsibility for a greater scope of services. It is not expected that new programs, or programs from small hospitals, will be able to meet all the must-have recommendations at program inception. However, the recommendations should serve as benchmarks and goals for all programs to strive for as soon as possible. We suggest that these recommendations be used as a starting point for strategic planning by existing programs and as a template for program development by hospitals in the planning phase. Users should look upon these recommendations as a work in progress; as the field matures, we anticipate future refinement will be needed.

TABLE 1. NATIONAL QUALITY FORUM PREFERRED PRACTICES FOR HOSPICE AND PALLIATIVE CARE

*A National Framework and Preferred Practices for Palliative
and Hospice Care Quality
A National Quality Forum (NQF) Consensus Report*

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 per day, 7 days a week**.
3. Provide **continuing education** to all health care professionals on the domains of palliative care and hospice care.
4. Provide adequate **training and clinical support** to assure that professional staff is 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 health care 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. Health care 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'/health care **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, decision making, 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.
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 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.
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.

TABLE 1. NATIONAL QUALITY FORUM PREFERRED PRACTICES FOR HOSPICE AND PALLIATIVE CARE (CON'T)

*A National Framework and Preferred Practices for Palliative
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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/decision maker** 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 decision making capacity, document the child's views and preferences** for medical care, including assent for treatment, and give them appropriate weight in decision making. Make appropriate professional staff members available to both the child and the adult decision maker for consultation and intervention when the child's wishes differ from those of the adult decision-maker.

RECOMMENDATIONS

<i>Domain</i>	<i>NQF^a</i>	<i>Must have</i>	<i>Should have</i>
1. Program Administration^A		Palliative care program staff integrated into the management structure of the hospital to ensure that program consideration of hospital mission/goals, processes, outcomes, and strategic planning are developed in consideration of hospital mission/goals.	Systems that integrate palliative care practices into the care of all seriously ill patients, not just those seen by the program.
2. Types of Services^B		A consultation service that is available to all hospital inpatients.	Resources for outpatient palliative care services, especially in hospitals with more than 300 beds. An inpatient palliative care geographic unit, especially in hospitals with more than 300 beds.
3. Availability^C	2	Monday–Friday inpatient consultation availability and 24/7 telephone support.	24/7 inpatient consultation availability, especially in hospitals with more than 300 beds.
4. Staffing^D	1, 5, 19, 20, 21, 22, 23	Specific funding for a designated palliative care physician(s). All program physicians must be board certified in hospice and palliative medicine (HPM) or committed to working toward board certification. Specific funding for a designated palliative care nurse(s), with advance practice nursing preferred.	

(continued)

<i>Domain</i>	<i>NQF^a</i>	<i>Must have</i>	<i>Should have</i>
		<p>All program nurses must be certified by the National Board for Certification of Hospice and Palliative Nursing (NBCHPN) or committed to working toward board certification.</p> <p>Appropriately trained staff to provide mental health services.</p> <p>Social worker(s) and chaplain(s) available to provide clinical care as part of an interdisciplinary team.</p> <p>Administrative support (secretary/administrative assistant position) in hospitals with either more than 150 beds or a consult service with volume > 15 consults per month.</p>	
5. Measurement^E	12, 13, 14, 15, 16	Operational metrics for all consultations. Customer, clinical and financial metrics that are tracked either continuously or intermittently.	
6. Quality Improvement^F	12, 13, 14, 15, 16	Quality improvement activities, continuous or intermittent, for (a) pain, (b) non-pain symptoms, (c) psychosocial/spiritual distress and (d) communication between health care providers and patients/surrogates.	
7. Marketing^G		Marketing materials and strategies appropriate for hospital staff, patients, and families.	
8. Education^H	3	Palliative care educational resources for hospital physicians, nurses, social workers, chaplains, health professional trainees, and any other staff the program feels are essential to fulfill its mission and goals.	
9. Bereavement Services^I	17, 30, 31	A bereavement policy and procedure that describes bereavement services provided to families of patients impacted by the palliative care program.	
10. Patient Identification^J		A working relationship with the appropriate departments to adopt palliative care screening criteria for patients in the emergency department, general med/surgical wards and intensive care units.	
11. Continuity of Care^K	7, 8, 28	<p>Policies and procedures that specify the manner in which transitions across care sites (e.g., hospital to home hospice) will be handled to ensure excellent communication between facilities.</p> <p>A working relationship with one or more community hospice providers.</p>	
12. Staff Wellness^L	4	Policies and procedures that promote palliative care team wellness.	

^aThe numbers in the NQF column represent the specific National Quality Forum Hospice and Palliative Medicine *Preferred Practice*. A National Framework and Preferred Practices for Palliative and Hospice Care Quality: A Consensus Report © 2006 National Quality Forum, www.qualityforum.org, Washington, DC.

Comments

- A. To effectively integrate palliative care services into hospital culture and practice, so that the program's mission is aligned with that of the hospital, the program must have both visibility and voice within the hospital management structure. This can best be accomplished by (1) ensuring that a program has a designated program director, with dedicated funding for program director duties and (2) a routine mechanism for program reporting and planning that is integrated into the hospital management committee structure.
- B. The three components of a fully integrated palliative care program are an inpatient consultation service, outpatient practice, and geographic inpatient unit. All three serve different but complementary functions to support patients/families through the illness experience. Because a consultation practice has the ability to serve patients throughout the entire hospital, this is typically recommended as the first point of program development.
- C. Patients, families and hospital staff need palliative care services that are available for both routine and emergency services.
- D. The following disciplines are essential to provide palliative care services: physician, nursing, social work and chaplaincy. In addition, mental health services must be available. Depending on the institution and staff, basic mental health screening services can be provided by an appropriately trained social worker, chaplain, or nurse with psychiatric training. Ideally a psychologist or psychiatrist are also available for complex mental health needs. Social work, chaplaincy, and mental health services can be provided by dedicated palliative care full-time equivalent positions or by existing hospital staff, although their work in support of the palliative care program will still need to be accounted and paid for, and not just "added on" to their existing job responsibilities.
- E. Providing evidence of the value of palliative care programs to patients, families, referring physicians and hospital administrators is critical for program sustainability and growth. Key outcome measures can be divided into four domains (examples provided):
- Operational Metrics: (number of consults, referring physician, disposition)
 - Clinical Metrics: (improvement in pain, dyspnea, distress)
 - Customer Metrics: (patient/family/referring physician satisfaction)
 - Financial Metrics: (cost avoidance, billing revenue, length of stay)
- F. Palliative care programs must be held accountable to the same quality-improvement standards as other hospital clinical programs.
- G. As a new specialty, the palliative care program is responsible for making its presence and range of services known to the key stakeholders for quality care.
- H. As a new specialty, the palliative care program is responsible for helping develop and coordinate educational opportunities and resources to improve the attitudes, knowledge, skills, and behavior of all health professionals.
- I. There are no currently accepted *best practice* features of bereavement services to recommend. Common elements present in many programs include telephone or letter follow-up, sympathy cards, registry of community resources for support groups and counseling services, and remembrance services. All programs are encouraged to develop a bereavement policy and make changes as needed through quality-improvement initiatives.
- J. In most hospitals, palliative care consultations originate from a physician order. To facilitate referrals for "at-risk" patients, many hospitals have begun adopting screening

TABLE 2. CONSENSUS PANEL

John Barkley, M.D., FCCP; Hospice and Palliative Care Charlotte Region
Janet Larson Braun, M.S.P.H., R.N.; Hospice of the Bluegrass
Gretchen Brown, M.S.W.; Hospice of the Bluegrass
Charles F. von Gunten, M.D., Ph.D.; San Diego Hospice and the Institute for Palliative Medicine
Todd R. Coté, M.D.; Hospice of the Bluegrass
Brian Cassel, Ph.D.; Virginia Commonwealth University
Margaret L. Campbell, Ph.D., RN, FAAN; Detroit Receiving Hospital and Wayne State University
Lyn Ceronsky, M.S., G.N.P.-B.C.; Fairview Health System
Phil Santa Emma, M.D.; Mt Carmel Health System
Sarah Friebert, M.D., Akron Children's Hospital
Amber Jones, M.Ed.; Palliative Care and Hospice Consultant.
Diane E. Meier, M.D., Mount Sinai Medical Center
Sean Morrison, M.D., Mount Sinai Medical Center
Sandra Muchka, R.N., M.S.N., A.C.H.P.N.; Medical College of Wisconsin
Timothy Quill, M.D., University of Rochester
Michael Rabow, M.D., University of California, San Francisco
Christine Ritchie, M.D., University of Alabama
Tom Smith, M.D., Virginia Commonwealth University
Lynn Spragens, M.B.A.; Spragens and Associates
Martha L. Twaddle, M.D., Midwest Palliative HospiceCare Center
David E. Weissman, M.D., Medical College of Wisconsin

criteria based on disease characteristics (e.g., metastatic cancer) or hospital utilization (e.g., three hospitalizations within 3 months). A system whereby “at-risk” patients are proactively identified can help ensure that patients in greatest need of palliative care services are effectively triaged.

- K. Coordination of care as patients move from one care site to another is especially critical for patients with serious, often life-limiting diseases, and is a cornerstone of palliative care clinical work.
- L. The psychological demands on palliative care staff are often overwhelming, placing practitioners at risk for burnout and a range of other mental health problems. Common examples of team wellness activities are team retreats, regularly scheduled patient debriefing exercises, relaxation-exercise training and individual referral for staff counseling.

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Address reprint requests to:
David E. Weissman, M.D.
Division of Neoplastic Diseases
Froedtert Hospital
9200 W. Wisconsin Avenue
Milwaukee, WI 53226

E-mail: dweissma@mcw.edu

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