

SAN FRANCISCO PALLIATIVE CARE TASK FORCE

ISSUE BRIEF #3

PALLIATIVE CARE QUALITY: OVERVIEW

Understanding what quality in health care means—its definition, application, and interpretation—is critical to comprehending, measuring, and improving health care. The Institute of Medicine (IOM) defines quality of care as: *The extent to which health services provided to individuals and patient populations improve desired health outcomes. The care should be based on the strongest clinical evidence and provided in a technically and culturally competent manner with good communication and shared decision-making. Quality care is safe, effective, patient-centered, timely, efficient, and equitable.*¹

The National Consensus Project (NCP) Clinical Practice Guidelines for Palliative Care, the Joint Commission Advanced Certification Program for Palliative Care, and the Centers for Medicare & Medicaid Services (CMS), affirm that measuring quality should be an essential component of all palliative care programs. As such, palliative care quality measurements are continually being refined to advance the goal of improving quality of life for patients and families.

The following summary of widely used and recognized palliative care domains, targets, and quality indicators is intended to provide members of the San Francisco Palliative Care Task Force with a framework for understanding and developing, short- and long-term recommendations that may directly, or indirectly, address the issue of quality.

Framework for Evaluating Quality

Quality is a complex issue. To examine and evaluate quality in health care, many organizations and systems use the Donabedian framework, which identifies three primary categories for collecting information related to quality: **structure** (the stable elements of the health care system in which care is delivered, e.g., hospital buildings, staff, financing, and equipment), **process** (what health care services are provided and the transactions between patients and providers throughout the delivery of health care), and **outcomes** (end results—the effects of health care—for the patient and family). Information from these categories can, in turn, be applied to relevant domains to guide evaluation design.

Applying this framework to palliative care, structural elements may include specific characteristics of programs (e.g., palliative clinic availability), providers (e.g., interdisciplinary members of the palliative care team), and tools (e.g., do-not-resuscitate policies). Processes may include technical aspects of care, such as appropriate prescribing and interpersonal

¹ Institute of Medicine, The Definition of Healthcare Quality and the Institute of Medicine (2012); see: <http://www.iom.edu/>

aspects of care (e.g., coordination among providers). Outcomes may include patient quality of life or symptoms, perceptions of care, or caregiver outcomes such as burden. Outcomes may also be categorized as overuse (e.g., use of chemotherapy at the end of life compared to national benchmarks), underuse (e.g., lower rates of hospice care), or appropriateness of care (e.g., accurately documenting patients’ preferences for care).²

NCP has integrated elements of this structure, process, and outcomes framework in its approach to addressing quality in palliative care.³ Table 1 presents NCP’s key elements of palliative care, Table 2 presents NCP’s eight clinical domains.

Table 1. National Consensus Project Key Elements of Palliative Care

Patient population	Population served includes all patients of all ages experiencing a debilitating chronic or life-threatening illness, condition, or injury.
Patient-family centered care	The uniqueness of each patient and family is respected, and the patient and family (as defined by the patient) constitute the unit of care.
Timing of palliative care	Ideally, palliative care begins at the time of diagnosis with a life-threatening or debilitating condition and continues through cure or until death and into a family’s bereavement period.
Comprehensive care	Palliative care uses a multidimensional assessment to identify and relieve suffering through the prevention or alleviation of physical, psychological, social, and spiritual distress. Palliative care requires the regular and formal clinical process of assessment, diagnosis, planning, interventions, monitoring, and follow-up.
Interdisciplinary team	Palliative care presupposes indications for, and provision of, interdisciplinary team evaluation and treatment in selected cases.
Attention to relief of suffering	The primary goal of palliative care is to prevent and relieve the burdens imposed by disease and its treatments and consequent suffering, including pain and other symptom distress.
Communication skills	Effective communication skills are a requisite in palliative care.
Skill in care of the dying and bereaved	Palliative care specialist teams must be knowledgeable about prognostication, signs and symptoms of imminent death, and the associated care and support needs of patients and their families before and after the death.
Continuity of care across settings	Palliative care is integral to all healthcare settings, and palliative care teams collaborate with professional and informal caregivers in each of these settings to ensure care coordination, communication, and continuity of palliative care across institutional and home-care settings.
Equitable access	Palliative care teams should strive to provide equitable access to palliative care for patients of all ages, diagnoses, and healthcare settings, regardless of race, ethnicity, sexual orientation, or ability to pay.
Quality assessment and performance improvement	Palliative care services should be committed to the pursuit of excellence and high-quality care, and palliative care teams should participate in regular and systematic evaluation of the processes of care and measurement of outcomes data using validated instruments.

² Dy, S.M. Measuring the quality of palliative care and supportive oncology: principles and practice. *The Journal of Supportive Oncology*, 2-13.11:4.

³ National Consensus Project for Quality Palliative Care Clinical Practice Guidelines for Quality Palliative Care 3rd edition (2013); see: http://www.nationalconsensusproject.org/NCP_Clinical_Practice_Guidelines_3rd_Edition.pdf

Table 2. National Consensus Project Eight Domains

- Structure and processes of care;
- Physical aspects of care, including targets of symptoms such as pain and function;
- Psychological and psychiatric aspects of care, including symptoms such as depression and delirium as well as grief and bereavement;
- Social aspects of care, such as caregiving and coping;
- Spiritual, religious, and existential aspects of care;
- Cultural aspects of care, such as cultural competency and use of a translator;
- Care of the patient at end-of-life; and,
- Ethical and legal aspects of care, such as advance directives.

NCP's domains for measuring quality are reflected in other nationally recognized sets of palliative care quality indicators, including the National Quality Forum, (www.qualityforum.org), the Agency for Healthcare Research and Quality (AHRQ) Quality Measures database (<http://www.ahrq.gov/>), and PEACE Measures (<http://www.med.unc.edu/pcare/files/recommended-quality-measures-and-data-collection>)—for PEACE indicators, see Appendix A.

In recent years, palliative care researchers and experts have been reexamining widely used quality indicators to evaluate whether they appropriately and effectively measure performance across domains, settings, and populations. In the Netherlands a dedicated analysis of existing quality indicators led to a final revised set of indicators that more fully addresses spiritual care, as well as support for relatives. The 33 indicators for palliative patient care and 10 indicators for support for relatives before and/or after the patient's death, were additionally determined to be applicable in different settings of palliative care, e.g., home, hospices, hospitals, nursing facilities, mental health institutions, etc., and more inclusive of outcome indicators (Appendix B).⁴

In the United States, the American Academy of Hospice and Palliative Medicine (AAHPM) and the Hospice and Palliative Nurses Association (HPNA) recently partnered together on the *Measuring What Matters* (MWM) consensus project. MWM's goal is to recommend a concise set of valid, clinically relevant, cross-cutting performance indicators to serve as a foundation of internal measurement for palliative care and hospice programs.⁵

To move closer to its goal of establishing a portfolio of palliative care quality measures for the United States, MWM first examined where quality deficits exist and then determined the best interventions to address those deficits and monitor quality over time. Through a phased process that has included input from a project Technical Advisory Panel and Clinical User Panel,

⁴ Claessen, SJJ., et al. A New Set of Quality Indicators for Palliative Care: Process and Results of the Development Trajectory, *Journal of Pain and Symptom Management*, 2011,42:2.

⁵ American Academy of Hospice and Palliative Medicine); see: <http://aahpm.org/quality/measuring-what-matters>

MWM has identified a current set of twelve, draft consensus measures that it anticipates reducing by project completion (Appendix C).

Although quality measures will continue to evolve, the following standards by which they are developed and tested are likely remain constant: **importance** (indicators are based on evidence and related to key quality domains and outcomes); **scientific acceptability** (the ability to produce consistent and believable results); **use and usability** (refers to indicators that are in current use and that generate information usable in quality activities), and **feasibility** (the extent to which data is available and can be readily obtained).

Appendix A. PEACE– Quality Indicators

QUALITY MEASURES BY DOMAIN

www.med.unc.edu/pcare/files/recommended-quality-measures-and-data-collection

Structure and Process of Care

- Use of standard questions to assess patient depression
- Percent of patients admitted to hospice or palliative care who have a screening for symptoms during the admission visit
- Policy/procedure specifying frequency with which pain & dyspnea should be assessed
- Percent of patients who had comprehensive assessment completed within 5 days of admission

Care for physical symptoms: pain

- Percent of patients screened for pain during the admission visit
- For patients who screened positive for pain, the percent with a clinical assessment within 1 day of screening
- For patients who screened positive for pain, the percent with any treatment within 1 day of screening
- For patients who screened positive for pain, the percent who had an order for regularly scheduled (not PRN) pain medication within 1 day of screening
- For patients who screened positive for pain, the percent with improvement within 1 day of screening
- For patients who screened positive for pain, the percent whose pain was at comfortable level within 2 days of screening
- Percent of patient with cognitive and language problems receiving pain assessment appropriate to communication needs

Care for physical symptoms: dyspnea

- Percent of patients who were screened for shortness of breath during the admission visit
- For patients who screened positive for dyspnea, the percent who receive treatment within 1 day of screening
- For patients who screened positive for dyspnea, the percent who improved within 1 day of screening
- For new ratings of shortness of breath ≥ 4 (on a 10 point scale), the percent with treatment (or satisfied) within 4 hours

Care for physical symptoms: other conditions

- For patients who screened positive for nausea, the percent of patients who receive treatment within 1 day of screening
- Percent of patients with bowel function assessed at least weekly
- For patients who screen positive for constipation, the percent who receive treatment within 1 day of screening
- Percent of patients on opioids for whom a bowel regimen is established
- Percent of patients on opioids who have a bowel regimen initiated within 1 day of opioid initiation

Care for psychological symptoms

- For patients who screen positive for depression, the percent who receive further assessment, counseling or medication treatment
- For patients diagnosed with depression, the percent who receive interpersonal or medication treatment within two weeks of diagnosis
- For patients who screened positive for anxiety, the percent who receive treatment within two weeks of diagnosis

Social aspects of care

- Percent of families reporting the hospice attended to family needs for information about medication, treatment and symptoms
- Percent of families who respond “Always” to question on Family/Friends Evaluation of how often family was kept informed about patient's condition

Spiritual aspects of care

- Percent of patients with chart documentation of a discussion of spiritual or religious concerns any time in the last week of life.

Cultural aspects of care

- Provision of interpreter or translators for non-English-speaking or deaf patients.

Care of the imminently dying

- Percent of patients who had moderate to severe pain on a standard rating scale at any time in the last week of life.
- Percent of families reporting they were informed of what to expect around the time of death.

Ethical and legal aspects of care

- Percent of patients with chart documentation of their preference for life-sustaining treatments
- Percent of patients with chart documentation of an advanced directive or discussion that there is no advanced directive
- Percent of patients with contact information for surrogate decision maker in chart
- Percent of patients with impaired decision-making (dementia, coma or other altered mental status) with documentation of surrogate decision maker in chart within 2 days of recognition of impaired decision making

Adverse events

Selected number of occurrences per 100 patient days:

- Note: 4 types of issues are tracked: falls, medication errors, DME issues (compliant, malfunction or error), and patient / family complaints)

Appendix B. A New Set of Quality Indicators for Palliative Care – The Netherlands

Quality Measures by Domain

Management of pain and other physical symptoms

- Percentage of patients with moderate to severe pain
- Percentage of patients with fatigue
- Percentage of patients with shortness of breath
- Percentage of patients with constipation
- Extent to which patients receive support for their physical symptoms (pain, fatigue, shortness of breath, and constipation)
- Extent to which patients receive help with physical care

Care for psychosocial well-being

- Percentage of patients with anxiety
- Percentage of patients who feel depressed
- Extent to which patients receive support when they feel anxious or feel depressed
- Extent to which patients receive attention from their caregivers
- Extent to which patients are satisfied with the counseling aspects of “politeness” and “being taken seriously”
- Extent to which patients experience respect for their autonomy
- Extent to which patients experience respect for their privacy.
- Extent to which direct relatives considered that the patient had the opportunity to be alone

Care for spiritual well-being

- Extent to which patients indicate that caregivers respect their life stance
- Extent to which patients indicate that they have access to a counselor for spiritual problems
- Extent to which relatives indicate that the patient had access to a counselor for spiritual problems
- Extent to which relatives indicate that the patient received support with preparations for saying goodbye
- Extent to which patients indicate that they feel that life is worthwhile
- Percentage of relatives who indicate that the patient died peacefully
- Percentage of relatives who indicate that the patient had accepted her/his approaching death
- Extent to which relatives indicate that there was attention and respect for the psychosocial and spiritual well-being of the patient

Generic aspects

- Extent to which patients in the last month before their death were in the location of their preference
- Percentage of patients who died in the location of their preference
- Extent to which patients know who the contact person is for the care
- Extent to which patients receive information about the expected course of the illness
- Extent to which patients receive information about the advantages and disadvantages of various types of treatments
- Extent to which patients indicate that they receive understandable explanations
- Extent to which patients indicate that they receive contradictory information
- Presence of documentation concerning the desired care and treatment at the end of life
- Extent to which relatives indicate that the patient was asked about her/his opinions with regard to end-of-life decisions
- Extent to which patients experience expertise and continuity
- Percentage of patients who receive medical aid soon enough

CONTINUED: Quality Indicators Concerning Support or Aftercare for Relatives by Domain

Care for psychosocial and spiritual well-being of relatives

- Extent to which, according to the direct relatives, attention was paid to their own psychosocial and spiritual well-being
- Extent to which the direct relatives felt that they were treated well in all respects by the caregivers
- Extent to which, according to the direct relatives, their autonomy was respected
- Extent to which the direct relatives had the opportunity to be alone with their relative

Generic (in the care for relatives)

- Extent to which direct relatives received information that was understandable and unambiguous at the time of the patient's death
- Extent to which direct relatives received information about the advantages and disadvantages of various types of treatment
- Extent to which direct relatives perceived the expertise of caregivers and the continuity of care

Aftercare

- Extent to which direct relatives felt supported by the caregivers immediately after the patient's death
- Extent to which direct relatives were informed about the possibilities of aftercare
- Extent to which a final conversation or discussion was held to evaluate the care and the treatment

Appendix C. Measuring What Matters – Quality Indicators

<http://aahpm.org/uploads/education/MWM%20Top%2012%20Measure%20Information%20and%20Comments.pdf>

Domain 1: Structure and Process of Care

- Measure 1: Hospice and Palliative Care– Comprehensive Assessment
Source: PEACE subset (Hanson 2012)
<http://www.med.unc.edu/pcare/resources/PEACE-Quality-Measures>

Domain 2: Physical Aspects of Care

- Measure 2: Pain Treatment (ANY)
Source: PEACE subset (Hanson 2012); <http://www.med.unc.edu/pcare/resources/PEACE-Quality-Measures>
- Measure 3: Screening for Physical Symptoms
Source: PEACE subset (Hanson 2012); <http://www.med.unc.edu/pcare/resources/PEACE-Quality-Measures>
- Measure 4: Dyspnea Screening and Management
Source: PEACE subset (Hanson 2012); <http://www.med.unc.edu/pcare/resources/PEACE-Quality-Measures>

Domain 3. Psychological and Psychiatric Aspects of Care

- Measure 5: Discussion of Emotional or Psychological Needs
Source: PEACE subset (Hanson 2012); <http://www.med.unc.edu/pcare/resources/PEACE-Quality-Measures>

Domain 4. Social Aspects of Care (No measures in this domain)

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

- Measure 6: Discussion of Spiritual/Religious Concerns
Source: NQF # 1647 / Deyta, LLC
http://www.qualityforum.org/Projects/Palliative_Care_and_End-of-Life_Care.aspx#t=2&s=&p=3%7C

Domain 6. Cultural Aspects of Care (No measures in this domain)

Domain 7. Care of the Patient at the End-of-Life

- Measure 7: Proportion Admitted to Hospice for Less than 3 Days
Source: NQF # 0216 / ASCO- American Society of Clinical Oncology
http://www.qualityforum.org/Projects/Cancer_Endorsement_Maintenance_2011.aspx#t=2&s=&p=2%7C3%7C
- Measure 8: Proportion with More than One Emergency Room Visit in the Last Days of Life
Source: NQF # 0211 / ASCO- American Society of Clinical Oncology
http://www.qualityforum.org/Projects/Cancer_Endorsement_Maintenance_2011.aspx#t=2&s=&p=2%7C3%7CMeasure 9: PEACE – Documentation of Surrogate Measure

Domain 8. Ethical and Legal Aspects of Care

- Measure 9: Documentation of Surrogate
Source: PEACE subset (Hanson 2012); <http://www.med.unc.edu/pcare/resources/PEACE-Quality-Measures>
- Measure 10: Treatment Preferences
Source: NQF # 1641 / PEACE Measure Set / Hospice Item Set
<http://www.med.unc.edu/pcare/resources/PEACE-Quality-Measures>
- Measure 11: Treatment Preferences Followed
Source: ACOVE Measure Set Website: <http://www.rand.org/health/projects/acove/acove3.html>

Global Measure

- Measure 12: The Family Evaluation of Palliative Care (FEPC)
Source: NHPCO Website: <http://www.nhpc.org/performance-measures/family-evaluation-palliative-care-fepec>