Quality Measures for Palliative Care in Patients With Cancer: A Systematic Review

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Abstract

Purpose: Quality assessment is a critical component of determining the value of medical services, including palliative care. Characterization of the current portfolio of measures that assess the quality of palliative care delivered in oncology is necessary to identify gaps and inform future measure development.

Methods: We performed a systematic review of MEDLINE/PubMed and the gray literature for quality measures relevant to palliative care. Measures were categorized into National Quality Forum domains and reviewed for methodology of development and content. Measures were additionally analyzed to draw summative conclusions on scope and span.

Results: Two hundred eighty-four quality measures within 13 measure sets were identified. The most common domains for

measure content were Physical Aspects of Care (35%) and Structure and Processes of Care (22%). Of symptom-related measures, pain (36%) and dyspnea (26%) were the most commonly addressed. Spiritual (4%) and Cultural (1%) Aspects of Care were least represented domains. Generally, measures addressed processes of care, did not delineate benchmarks for success, and often did not specify intended interventions to address unmet needs. This was most evident regarding issues of psychosocial and spiritual assessment and management.

Conclusion: Within a large cohort of quality measures for palliative care is often a focus on physical manifestations of disease and adverse effects of therapy; relatively little attention is given to the other aspects of suffering commonly observed among patients with advanced cancer, including psychological, social, and spiritual distress.

Introduction

As highlighted in the ASCO Provisional Clinical Opinion,¹ palliative care improves outcomes for patients with advanced cancer, including improved quality of life, reduced symptom burden, reduced health care resource use, and potentially lengthened survival.² Standardization of palliative processes and methods to deliver state-of-the-art palliative care services is critical if similar outcomes are to be achieved.³ Oncologists and palliative medicine clinicians are increasingly collaborating on palliative care delivery to patients with cancer.⁴ To sustain these efforts and demonstrate value, the nature of palliative care interventions and processes delivered should be promoted, and impact measured.⁵ Quality measures can be used to assess the degree to which the cancer community conforms to expected best-practice palliative care, and to monitor change as cancer care delivery models are updated. This is especially important as public and professional awareness of the role of palliative care in oncology increases, and public reporting of quality measure conformance becomes reality.⁶

The ASCO Quality Oncology Practice Initiative (QOPI) measures are the most widely used cancer quality metrics in the United States^{7,8}; these include a separate module on end-of-life care. Although important, this represents only a small subset of the total collection of quality measures relevant to palliative care. We therefore conducted a systematic review of all palliative care quality measures applicable to patients with cancer to

understand the total landscape of measures and identify content gaps for quality assessment in routine oncology practice.

Methods

Literature Search and Selection

We searched MEDLINE/PubMed for English-language literature from January 1995 through March 2012 using the terms “palliative care,” “end-of-life care,” “supportive care,” “quality assessment,” “quality improvement,” “quality measurement,” “quality metrics,” “indicators,” “measures,” or “preferred practices.” For the purposes of the review, we will use the single phrase “quality measures” as the inclusive term to indicate health care tools that quantify the consistency of care delivery within a population eligible for the process. We limited those quality measures included within our review to those applicable to palliative care settings, including all those involving chronic, advanced, or serious illness. This reflects the newer, accepted definition of those eligible for palliative care upstream from the end-of-life setting.

Searches focused on process measures as defined within the Donabedian model⁹; structural and outcome measures were excluded. All searches were conducted during May 2011, with an update in October 2012. We used methodology from the Preferred Reporting Items for Systematic Re-

views and Meta-Analyses Statement to guide our search, analyses, and reporting.¹⁰

Study Abstraction and Analysis

Three trained reviewers (A.H.K., J.M., M.G.) with clinical backgrounds in medical oncology, internal medicine, family medicine, and pulmonary and critical care participated in study selection. Research studies, review articles, or Internet documents were accepted if they included specific quality indicators or measures. Measure sets that focused on diagnostics, therapeutics, therapy for adverse effects or complications of chemotherapy, or guidelines for clinical care without methodology for quality conformance determination were excluded. Also excluded were quality measure sets aimed at specific noncancer disease conditions (eg, heart failure), those that included supportive or palliative care only as a minor component, those that could not be applied to most cancer conditions or disease states, or those in which the measure set was primarily for licensure or accreditation purposes.

Each measure was categorized along the National Quality Forum eight domains of palliative care.¹¹ These are: Physical Aspects of Care, Structure and Processes of Care, Care of the Imminently Dying, Ethical and Legal Aspects of Care, Psychiatric and Psychological Aspects of Care, Social Aspects of Care, Spiritual/Existential Aspects of Care, and Cultural Aspects of Care. Quality measures were abstracted for methods of measure development, relevant populations, numerator (population successfully satisfying measure), and denominator (eligible population for measure). To simplify for the reader, we refer to all quality indicators, metrics, guidelines and measures in our analysis and in this article as “quality measures.”

Results

Our search flow diagram is presented in Figure 1. We found 13 sets of quality measures containing 284 individual measures (listed in Data Supplement) involving palliative care that could be used in patients with cancer; 16 of these measures were from the ASCO QOPI measure set (Table 1). Systematic and other reviews by the Agency for Healthcare Research and Quality,¹² Lorenz et al,^{13,14} and Pasman et al¹⁵ are presented for reference. The Center to Advance Palliative Care operational metrics^{16,17} and National Hospice and Palliative Care Organization National Data Set were excluded because of their focus on structural and operational metrics of consultative palliative care services. Because specific measures for good practice were proposed by the Center to Advance Palliative Care in “Palliative Care Clinical Care and Customer Satisfaction Metrics,”¹⁸ this document was included in our review. The Joint Commission Standards for Advanced Certification for Palliative Care and American College of Surgeons Commission on Cancer 2012 Standards were also excluded as a result of their use primarily for accreditation purposes.

Included measure sets and their characteristics are summarized in Table 1. Generally, measures were constructed from either retrospective chart abstraction and/or expert consensus, were generated in academic environments, and originated from

Figure 1. Study inclusion flowchart.

Western countries. Sets include a range of seven to 41 individual measures. No measure sets prioritized or weighted individual measures for value or utility as compared with others within the same set. All measure sets were designed for retrospective abstraction and analysis through clinical or administrative registries or databases. Fifty-four percent of measures could be obtained through patient-reported means, and largely this could be achieved through prospective data collection strategies. This remains an important point, as patient-reported outcomes infrastructure in oncology is maturing to assist in the practicality of data collection efforts.¹⁹

Measures by Domain

We grouped all 284 quality measures into one of eight National Quality Forum domains and then further categorized each measure into a subdomain. These are summarized in Table 2.

Physical Aspects of Care

The most common type of quality measure involves assessment, management, or follow-up of a burdensome symptom. This domain comprises 35% (100 of 284) of all measures, with the most common symptoms addressed being pain (36%), dyspnea (26%), comprehensive assessment (10%), and nausea (9%). Other symptoms addressed by quality measures include fatigue, diarrhea, skin rash, delirium, and constipation, as well as symptoms related to anemia, anorexia, and dysphagia. Generally, it is recommended that symptom assessment techniques involve patient self-report, use numeric rating scales, document results of screening, and frequently reassess severity and burden. Symptom management measures generally did not specify a type of treatment, were process measures that outlined the necessity for treatment when certain severity thresholds were met, and

Table 1. Quality Measure Set Summary

Measures Set	Development Methodology	Setting for Use	Domains	No. of Measures
ASCO QOPI ⁷ Care at End-of-Life measures from Spring 2011	Literature review and expert consensus	Outpatient oncology	P, ID	16
Cancer Quality ASSIST ²¹	Literature review, expert consensus, chart abstraction for validity/reliability	Advanced cancer, both inpatient and outpatient	P, EL	41
Acute Care of the Vulnerable Elderly (ACOVE) ²⁵	Literature review, expert consensus	Vulnerable elderly, inpatient	P, Psy, EL	21
Claessen et al, "New Set of Quality Indicators for Palliative Care: Process and Results of the Development Trajectory" ²²	Literature review, expert consensus, focus groups with patients/caregivers, clinical feasibility/usability testing, caregiver interviews for feasibility/usability	Adult palliative care patients, all settings	S&P, P, Psy, Soc, Sp, EL, ID	33
Miyashita et al, "Identification of Quality Indicators of End-of-Life Cancer Care from Medical Chart Review using a Modified Delphi Method in Japan" ²⁴	Expert consensus	Cancer patients in end of life, inpatient	All eight domains	30
Clinical Practice Guidelines for Quality Palliative Care (ed 2) by the National Consensus Panel ²⁶	Literature review, expert consensus	All populations, all settings	All eight domains	21
National Quality Forum, "A National Framework and Preferred Practices for Palliative Care and Hospice Quality" ¹¹	Literature review, expert consensus	All populations, all settings	All eight domains	35
Center to Advance Palliative Care, "Palliative Care Clinical Care and Customer Satisfaction Metrics" ¹⁸	Literature review, expert consensus	All populations, consulting palliative care team comanagement model (mostly inpatient) and inpatient palliative care units	S&P	7
Twaddle et al, "Palliative Care Benchmarks from Academic Medical Centers" ³⁰ from the University Health Consortium	Literature review, expert consensus, chart validation	Adults with "high mortality diagnoses," LOS > 4 d, and two prior admissions in preceding 12 mo; inpatient (ICU)	S&P, P, Psy, Soc	11
Grunfeld et al in "Towards Using Administrative Databases to Measure Population-Based Indicators of Quality of End-of-Life Care: Testing the Methodology" ³¹	Literature review, expert consensus, chart validation and reliability	Advanced cancer in all settings	S&P	7
The Robert Wood Johnson Foundation Critical Care Workgroup, "Proposed Quality Measures for Palliative Care in the Critically Ill" ³²	Literature review and expert consensus	All populations within any critical care unit (eg, MICU, SICU, TICU)	All 8 domains	18
Nelson et al, "Veterans Health Administration Transformation of the Intensive Care Unit Quality Bundle" ³³	Literature review, expert consensus, pilot testing in ICU's for feasibility	All populations in ICU	S&P, P, Psy, Sp, EL, Soc	10
PEACE ²⁰	Literature review, expert consensus	All populations and settings within palliative care, with emphasis on hospice	All 8 domains	34

Abbreviations: ASSIST, Assessing Symptoms Side Effects and Indicators of Supportive Treatment; C, Cultural Aspects of Care; EL, Ethical and Legal Aspects of Care; ICU, intensive care unit; ID, Care of the Imminently Dying; MICU, medical intensive care unit; P, Physical Aspects of Care; PEACE, Prepare, Embrace, Attend, Communicate, and Empower; Psy, Psychiatric and Psychological Aspects of Care; QOPI, Quality Oncology Practice Initiative; S&P, Structure and Processes of Care; SICU, surgical intensive care unit; Soc, Social Aspects of Care; Sp, Spiritual and Existential Aspects of Care; TICU, trauma intensive care unit.

stressed documentation of efficacy although definitions for success were infrequently mentioned. Forty-four percent of all ASCO QOPI End-of-Life metrics fall into this domain.

Structure and Processes of Care

Aspects of care delivery characteristics account for 22% (63 of 284) of all quality measures; this category includes many aspects of the palliative care evaluation, including issues of performing a comprehensive assessment, ensuring adequate communica-

tion, and standardizing the components of palliative care. Subdomains include rural access to specialized care through telehealth; communication between providers, patients, and members of the interdisciplinary teams; need for continuous and timely care; and competency within palliative care domains among all care providers. The competency subdomain consists of 10 measures (16%), generally referring to a palliative care team but not explicitly delineating how competencies among oncologists could be assured or measured. Another subdomain,

Table 2. Scope of Quality Measures Within Domains

National Quality Forum Domain	Percentage of Total Measures	Elements Included in Quality Measures
Physical Aspects of Care	35	General symptom assessment and management, pain, dyspnea, fatigue, diarrhea, delirium, constipation, oral care, bowel and bladder care, anemia, anorexia or dysphagia, skin rash, nausea/vomiting
Structure and Processes of Care	22	Access, contact person, communication, children's needs, healthcare utilization, continuity of care, timeliness of care, discharge planning, team structure, standardization of assessment, visitation policy, care withdrawal, clinical self-care, competency, care settings, adverse events
Psychiatric and Psychological Aspects of Care	7	Psychosocial support, caregiver depression, depression assessment and treatment, anxiety assessment, grief and bereavement
Cultural Aspects of Care	1	Meeting communication needs, delivering culturally sensitive care
Spiritual Aspects of Care	4	Spiritual support, value of life, spiritual assessment, spiritual needs management, religion assessment
Social Aspects of Care	7	General assessment and management, family satisfaction of care, caregiver stress, support from caregiver, family's preferences
Care of the Imminently Dying	7	Pain at EOL, information at EOL, impending death recognition, peace at death, post-death care, locations/teams of care
Ethical and Legal Aspects of Care	17	Respect, insight into illness, impaired capacity, advance care planning, surrogate decision maker, advance directive continuity, following patient preferences, patient participation in advance care planning, informed consent, ethics

Abbreviation: EOL, end of life.

centered on issues of a comprehensive evaluation, includes 11 (17%) measures largely from the National Quality Forum that emphasize the need for a documented and shared plan of care.

Care of the Imminently Dying

This domain attends to many of the issues faced by patients with limited prognosis and their loved ones, including care both near and after death. Encompassing 7% (20 of 284) of all measures, this domain largely consists of process measures involving which teams should be involved in delivery of care (eg, appropriate hospice referral) or satisfaction of the bereaved after the patient's death. For example, nine QOPI measures that outline the need for appropriate hospice or palliative care referral, especially more than 3 days before death, constitute 40% of the whole domain. Quality measures that in some way require family input comprise 20% of this domain, often stated as "Percentage of relatives who indicate that..." In addition, avoiding chemotherapy administration within the last 2 weeks of life and adequately managing pain within the last week of life are emphasized in the QOPI and PEACE²⁰ measure sets, respectively. Notably, appropriateness of other treatments with limited value (eg, percutaneous feeding tubes) or resource use (eg, frequent hospital admissions) are not mentioned within the specifics of measures.

Ethical and Legal Aspects of Care

This domain contains 48 (17%) measures, which include a broad portfolio of quality measures related to advance care planning and patient autonomy. Included among advance care planning measures are 12 (25%) that specifically address the need for advance directives and six (13%) that outline the need for surrogate decision makers or health care proxies. A large component (40%) of this portfolio also includes following patient wishes regarding care preferences, including respect for autonomy and privacy. This often includes documenting patient goals of care and preferences for feeding interventions and life-sustaining medical procedures. Also emphasized within the

rubric of patient autonomy is proper informed consent, such as before chemotherapy, as mentioned in Quality ASSIST²¹ and "various types of treatments" from Claessen et al.²² Largely, this domain emphasizes both the process of conducting discussions to establish advance care plans or identify surrogate health care decision makers and the necessity of documenting such processes and the outcomes of these conversations. Also, the need for continuity of the results of these discussions, such as the persistence of documentation of code status among all medical records, was emphasized throughout these measures.

Psychiatric and Psychological Aspects of Care

This domain, which includes general psychosocial distress in addition to diagnoses of depression or anxiety among patients and caregivers, consisted of 7% (20 of 284) of all quality measures. Seven measures (35%) include the general need for a comprehensive and timely psychosocial assessment of patients; four measures (20%) explicitly address needs of caregivers and families. Four measures (20%) involve timely treatment of depression, although no measures recommended any single modality of treatment, including any references to pharmacologic agents, types of counseling, or expertise or training background of those involved in treatment programs. This domain largely leaves the roles of social workers, counselors, psychologists, or psychiatrists within palliative oncology care undefined. Adherence to this domain may meet the Commission on Cancer credentialing standard for distress screening in oncology.²³

Social Aspects of Care

Nineteen measures (7%) address support to caregivers and families. Within this domain seven measures (37%) outline processes for performing an interdisciplinary assessment of social needs and family relationships. This domain includes the most remarkable differences in scope and content related to the backgrounds of the authors. For example, four measures from Miyashita et al²⁴ from Japan explicitly address the preferences of families around issues of place of care, explanation of medical

condition, preferences or expectations, or care strategy; no other measure sets emphasized the preferences of caregivers to this extent, reflecting the importance of caregiver values in Eastern traditions. Of interest, only one quality measure addressed assessment of caregivers for financial, physical, or emotional stress. This was from the Acute Care of the Vulnerable Elderly²⁵ set and limits the assessment to patients who are terminally ill or have very limited function. Aspects of assessing roles and burdens of nonfamily caregivers and social groups were largely not addressed among measures.

Spiritual and Existential Aspects of Care

Issues of spiritual assessment and support are addressed in this set of quality measures, which comprise 4% (10 of 284) of all measures. Within this domain, most measures (70%) involve some aspect of service provision or assessment, including terms like “offered,” “had access,” “there was attention,” “discussion,” or “assessed.” Notably, few details surrounding issues of spiritual distress management, expertise or background of individuals providing spiritual care, or even definitions of the components of a thorough spiritual care assessment or intervention plan are provided. Interestingly, only one measure from Miyashita et al²⁴ mentioned documenting details on the level of patient religion; largely spirituality remained an imprecise area for “receiving a response on the best available evidence” (National Quality Forum¹¹) which is “skillfully and systematically applied” (National Consensus Panel²⁶). Notably, the role of health care or lay chaplains and interplay with clinical care providers were not addressed, leaving several unanswered questions about the responsibility and role among various clinical team members in providing spiritual care.

Cultural Aspects of Care

The least addressed of the domains, cultural concerns were the subject of only four quality measures (1%). The two populations mentioned in these measures were those with “cognitive and language problems” and “non-English-speaking or deaf patients,” both from the PEACE measure set.²⁰ The provision of “assessment appropriate to communication needs” and “interpreter or translators” were the most detailed any measure requiring an intervention became; one measure each from the National Quality Forum and National Consensus Panel only mentioned meeting needs “in a culturally-sensitive manner.” The exact components of both the assessment and delivery of culturally sensitive care, including those specific to race, ethnicity, or ethical principles that govern care (eg, less focus on patient autonomy *v* family shared decision making in Eastern cultures²³) largely remain unaddressed.

Discussion

We identified 284 individual performance measures among 13 measure sets with significant variation in breadth and depth of National Quality Forum domains addressed. QOPI measures constitute 6% of the total cohort.

There are notable areas for refinement and improvement in the current cohort of quality measures for palliative care in oncology. First, although the number of quality measures for end-of-life and palliative care has grown significantly, the scope and breadth of these measures remain quite focused on a limited set of symptoms, including pain and dyspnea. Other burdensome symptoms, such as fatigue, anorexia, and depression, which are common in advanced cancer settings, are rarely addressed by current quality measures.²⁷ Second, although the National Quality Forum outlines eight dimensions for quality in palliative care, current measures largely address only two of these domains: Physical Aspects of Care and Care of the Imminently Dying. As new measures are developed, increased attention to other aspects of patient distress must be given to ensure that all sources are assessed and managed. Third, an important opportunity exists for membership organizations like ASCO to propose new domains for quality measurement. These new measures could reflect the wealth of new evidence generated within palliative care, such as the importance of information sharing (eg, “Patients understand to their satisfaction details of their cancer, including but not limited to clinical stage” or “Patients are aware of clinical trial options for which they are eligible”); prognostic understanding (eg, “Patient understand to their satisfaction and in the terms they prefer the predicted prognosis of their cancer”); and communication between clinicians, clinical teams, patients, and caregivers (eg, Patient satisfied with quality of communication between care team).

Importantly, several unanswered questions and areas for further study still remain. As reflected by our review, the sheer number of quality measures is overwhelming, and a core set of these measures prioritized by impact of adherence on important patient-centered outcomes is missing. We have previously demonstrated that adherence to two QOPI quality measures, addressing comprehensive symptom assessment and assessment of emotional well-being, correlate with higher quality of life.²⁸ Although this begins to prioritize measures based on an ability to improve outcomes, studies that prospectively test these findings in settings outside of community-based palliative care, and in the community oncologists’ office, are needed. What also remains unclear is how measures may be differentially applicable in more upstream settings, or in different parts of the cancer illness trajectory. A recent collaborative summit began to answer some of these questions. In a partnership between ASCO and other foundations, attendees at the Clinical Oncology Collaborative Measures Summit produced 10 high-priority topics for cancer quality measure development. This was one of the first efforts to identify “cross-cutting” quality measures that identify best practices across the care continuum, disease states, and populations.²⁹

Oncologists may also wonder how to practically implement these quality measures into busy clinical practice. Borrowing from the practices of specialty palliative care, a focus on regular symptom assessment, timely symptom management, evaluation of goals of care and advance care planning, and understanding what a “good future” looks like for the patient and their caregivers is an excellent place to start. Apart from the

specific measures used by payers in value-based payment programs, spending too much effort on finding the “perfect” measure may, in fact, be the “enemy of the good.” A practical approach involves identifying a core set of quality measures tailored to the priorities and needs of local practices and patients, coordinating these data collection steps with collaborators to ensure matching areas are measured, and then using these data to inform quality improvement efforts to address areas for optimization. For most, the QOPI measures addressing palliative care provide a good model.

In summary, a large cohort of measures for quality assessment of palliative care in cancer patients has been reported. Common themes shared among the measures include the need for standardized assessment, timely interventions, and regular documentation of processes. Oncology-driven quality and outcomes research is needed to further link quality-based care with improved patient experiences. As new quality measures are developed, recognized gaps must be addressed to provide comprehensive, patient-centered, high-quality palliative care.

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ASCO Celebrates 50 Years of Advancing Progress Against Cancer

This historic year, as ASCO proudly commemorates its 50th anniversary and decades of evolutionary growth, the Society also celebrates the significant progress that has been made against cancer throughout history. ASCO's anniversary website, CancerProgress.Net, chronicles these achievements and more. We invite you to visit the upgraded Cancer Progress Timeline to explore advances in 18 different cancers and several types of care, peruse stories about ASCO's evolution and progress in the field, check out the site's new social media features, and vote on the most significant milestones in the field. You can also follow ASCO on ASCO Connection, Twitter, and Facebook to join in on the conversation about progress.

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