

Center to Advance Palliative Care Palliative Care Clinical Care and Customer Satisfaction Metrics Consensus Recommendations

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Abstract

Data collection and analysis are vital for strategic planning, quality improvement, and demonstration of palliative care program impact to hospital administrators, private funders and policymakers. Since 2000, the Center to Advance Palliative Care (CAPC) has provided technical assistance to hospitals, health systems and hospices working to start, sustain, and grow nonhospice palliative care programs. CAPC convened a consensus panel in 2008 to develop recommendations for specific clinical and customer metrics that programs should track. The panel agreed on four key domains of clinical metrics and two domains of customer metrics. Clinical metrics include: daily assessment of physical/psychological/spiritual symptoms by a symptom assessment tool; establishment of patient-centered goals of care; support to patient/family caregivers; and management of transitions across care sites. For customer metrics, consensus was reached on two domains that should be tracked to assess satisfaction: patient/family satisfaction, and referring clinician satisfaction. In an effort to ensure access to reliably high-quality palliative care data throughout the nation, hospital palliative care programs are encouraged to collect and report outcomes for each of the metric domains described here.

Introduction

THE LAST 10 YEARS HAVE SEEN the establishment and revision of clinical practice guidelines and frameworks for preferred palliative and end-of-life practices developed by consensus and best-evidence review processes. These include the National Consensus Project for Quality Palliative Care *Clinical Practice Guidelines*, the National Comprehensive Cancer Network *Advanced Cancer and Palliative Care Treatment Guidelines for Patients*, the National Quality Forum *National Framework and Preferred Practices for Palliative and Hospice Care Quality*, and the Institute for Clinical Systems Improvement *Palliative Care Guideline*.¹⁻⁴ A core feature of all these documents is an emphasis on measuring and improving the quality of care for seriously ill patients and their families.

As a relatively new specialty, hospice and palliative medicine must be held to the same standards of accountability as others, but we lack high-quality research from which to draw conclusions.⁵⁻¹⁶ There are scant data demonstrating that the presence of specific processes, or measurement of specific outcomes in hospice and palliative medicine reproducibly leads to improved care.⁵ Furthermore, there are a host of

methodological problems in measuring palliative care clinical quality and customer satisfaction.^{13,17-20} However, in spite of the existing problems, the need to measure what we do is essential, because patients and families deserve the high standards of care promised by our palliative care programs. In addition, as palliative care programs are required to defend their existence in an era of tightening financial constraints, longitudinal data that can track program impact have become critical to ensuring sustainability.²¹

Fortunately, there has been extensive work on palliative care quality metrics over the past 15 years including individual institution and cooperative research projects in the United States, Canada, Great Britain, and elsewhere, to evaluate various tools and assessment methodologies.^{6-11,17,22-24} Many validated tools are now available spanning the spectrum of pain and symptom management, care coordination, and patient/family satisfaction.^{6,25-29}

Since 2000, the Center to Advance Palliative Care (CAPC) and its nine Palliative Care Leadership CentersSM have provided outreach and technical assistance to more than 1300 U.S. hospitals. To ensure program quality and sustainability, CAPC has stressed that programs must measure key

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TABLE 1. METRIC CATEGORIES FOR PALLIATIVE CARE PROGRAMS

<i>Domain</i>	<i>Examples</i>
Operational metrics	Date of consult, diagnosis, referring clinician/service, patient age, patient gender, disposition, hospital length of stay
Clinical metrics	Symptom control scores, psychosocial assessment scores
Customer metrics	Satisfaction survey data: patient, family, referring clinician
Financial metrics	Daily preconsultation and postconsultation hospital cost, net loss/gain for inpatient deaths, case-mix index

operational, clinical, customer and financial data (Table 1). In 2008 a consensus panel of CAPC staff, consultants, and Palliative Care Leadership CenterSM (PCLC) faculty was convened to address the following question: What clinical and customer metrics are important for palliative care programs to track in assessing the quality of clinical care and the satisfaction of the customers who utilize palliative care services?

The purpose of this consensus report is to provide a framework for program directors to think about program evaluation in the realm of clinical care and customer satisfaction so as to demonstrate program impact for stakeholders. This paper is focused on measuring the quality of services provided by the consulting palliative care team (in a comanagement model), or a primary palliative care service on an inpatient palliative care unit. We are not suggesting these metrics be used across an entire institution to measure global aspects of palliative care, although certain elements could be adapted for that purpose. The metrics are also not designed to capture data that is not in the control of the palliative care team (e.g. frequency of recommendations acted upon by the referring clinician). This work builds upon the currently

available clinical practice guidelines, and provides additional specific and actionable information for individual palliative care programs.

Consensus Process

Panel members include clinicians and researchers from the nine Palliative Care Leadership Centers, all of whom are actively engaged in teaching principles of palliative care program development, operation, and growth to staff from hospitals and hospices in the United States. Additional individuals were invited to join who have worked in a consulting role to CAPC since 2000. The panel included interdisciplinary representation from academic, Veterans Health Administration and community hospital settings, single hospitals and large health systems, adult and pediatric programs, and programs coordinated by hospice agencies and hospitals (see Appendix A). Previous work by this panel has included recommended operational metrics for palliative care inpatient units and consultation services as well as the operational standards for hospital palliative care programs.³⁰⁻³²

In the realm of clinical quality, measures can include structure, process and outcome metrics. The panel primarily considered process and outcome measures, as the major palliative care structural metrics have been previously identified.^{1,2,28} Process measures refer to interactions between the patient and health care institution/provider, for example, charting a daily pain assessment. Outcome measures refer to a patient's subsequent health status, for example, a reduction in symptom distress. Because of the paucity of palliative care outcome measurement data, this report focuses primarily on process measures.

After an Ovid-MEDLINE and PubMed literature review, initial options for the domains of measurement were circulated, comments received, and revisions made and recirculated until consensus was reached. For clinical metrics, the consensus panel agreed upon four key measurement domains that represent the core of inpatient palliative care clinical services (Tables 2-5):

TABLE 2. SYMPTOM ASSESSMENT AND MANAGEMENT DOCUMENTATION

<i>What data should be measured?</i>	<i>Process measure</i>	<i>Outcome measure</i>	<i>Data collection tool examples (Table 6)</i>
Symptom assessment documented on initial encounter ^{a-c}	Frequency of documentation Missing elements within documentation	Symptom scores	A, B, C, D
At least daily reassessment documented for moderate to severe symptoms	Frequency of documentation Missing elements within documentation	Change in symptom scores over time	A, B, C, D
Reassessment of all symptoms documented no less than every three days	Frequency of documentation Missing elements within documentation	Change in symptom scores over time	A, B, C, D
Symptom management plan(s) documented for all moderate to severe symptoms	Frequency of documentation Missing elements within documentation		Chart review

^aMinimum list for adult patients includes: pain, nausea, delirium, dyspnea, constipation, mood (anxiety/depression), appetite, fatigue. Other analysis of total symptom burden, or number of moderate to severe symptoms at the initial encounter, can be helpful data for programs to demonstrate the need for palliative care services.

^bPrograms may wish to use additional validated tools for a more thorough assessment of individual symptoms (e.g. Beck Depression Inventory for depression).

^cProgram should consider adopting tools that can be used for patients who cannot self-report symptoms.

TABLE 3. DOCUMENTATION OF PATIENT-CENTERED GOALS OF CARE/GOALS OF TREATMENT DISCUSSION

<i>What data should be measured?</i>	<i>Process measure</i>	<i>Outcome measure</i>	<i>Data collection tool examples (Table 6)</i>
Goals of care/goals of treatment documentation ^{a,b}	Frequency of documentation Missing elements within documentation		E

^aFor consultations, depending on the question from the referring clinician, a goal of care/goal of treatment discussion may not be indicated.

^bThe documentation should include these features:

- Diagnosis, prognosis and treatment options reviewed
- Goals of care/goals of treatment identified
- Preferred setting of care identified
- Immediate and short-term plans to meet the identified goals
- Advance care planning
- If a written advanced directive (AD) exists, it is reviewed and placed in the chart along with notation of any patient-defined special instructions
- If patient desires to complete an AD and has not yet done so, plans for its completion are documented
- The patient’s preferences about a surrogate decision maker if he or she loses capacity in the future are identified and information recorded
- If patient declines to pursue an AD, the reason for this decision is recorded

TABLE 4. DOCUMENTATION OF SUPPORT TO PATIENT AND CAREGIVERS

<i>What data should be measured?</i>	<i>Process measure</i>	<i>Outcome measure</i>	<i>Data collection tool examples (Table 6)</i>
Support to patient and caregivers documentation ^a	Frequency of documentation Missing elements within documentation		F, G, H

^aDocumentation of the following support elements should include:

- Primary patient caregiver is identified
- The patient and caregiver needs are identified
- The patient and caregiver needs are met, and/or strategies are initiated to address unmet needs; follow-up actions are defined and documented (e.g., social worker, chaplain or psychology consulted)

TABLE 5. TRANSITION MANAGEMENT DOCUMENTATION

<i>What data should be measured?</i>	<i>Process measure</i>	<i>Outcome measure</i>	<i>Data collection tools (Table 6)</i>
Transition management documentation ^a	Frequency of documentation Missing elements within documentation Plan is documented for palliative care follow-up across settings Advance directives follow patient across care settings		I, J, K

^aDocumentation of communication across care sites (e.g., hospital to home hospice):

- The goals of care/goals of treatment
- Preferred methods of communication with patient/family
- Advance directive information
- Name of the surrogate decision maker and contact information
- Following clinician and contact information
- Symptom management plan, including up-to-date medication information
- Caregiver needs
- Follow-up appointments
- Community services engaged

- Assessment and management of physical/psychological/spiritual symptoms.
- Establishment of patient-centered goals of care.
- Support to patient and family caregivers.
- Management of transitions across care sites.

For customer metrics, consensus was reached around two domains to assess customer satisfaction, patient/family satisfaction and referring clinician satisfaction. Programs are

urged to work with their institutional quality departments, because some of these data may already be available through existing measurement systems (e.g., Press Ganey)

Following the consensus on domains, a discussion ensued to decide whether or not to recommend specific measurement tools. The panel decided that there was insufficient consensus among measurement researchers to make specific recommendations among the many excellent validated tools; instead the panel opted to list some of the more commonly

TABLE 6. EXAMPLES OF DATA COLLECTION TOOLS FOR MEASURING PATIENT CARE QUALITY

A. Memorial Symptom Assessment Scale^a www.npcrc.org/resources/resources_show.htm?doc_id=376168
B. Edmonton Symptom Assessment Scale^a www.npcrc.org/resources/resources_show.htm?doc_id=376168
C. Palliative Outcome Scale^a www.kcl.ac.uk/schools/medicine/depts/palliative/qat/posv2.html
D. Bedside Confusion Scale www.cancer.gov/cancertopics/pdq/supportivecare/delirium/HealthProfessional/page5 ^a
E. Family Conference Note (Fairview)^b www.capc.org/tools-for-palliative-care-programs/clinical-tools/
F. Social Worker Note; Patient Care and Needs Assessment (Central Baptist)^b www.capc.org/tools-for-palliative-care-programs/clinical-tools/
G. Social Worker Assessment (Central Baptist)^b www.capc.org/tools-for-palliative-care-programs/clinical-tools/
H. Spiritual Care Assessment (Central Baptist)^b www.capc.org/tools-for-palliative-care-programs/clinical-tools/
I. Care Transitions Measure (Care Transitions Program)^a www.lumetra.com/uploadedFiles/resource-center/tools/care_transitions/CTM-15.Measure.Scoring.pdf
J. Physician Orders for Life Sustaining Treatment Paradigm (POLST)^c www.ohsu.edu/ethics/polst/developing/implementation+materials.htm
K. Medical Orders for Life Sustaining Treatment (MOLST)^c http://www.health.state.ny.us/professionals/patients/patient_rights/molst/

^aSee Carolinas Center for Medical Excellence²⁵ for validation data.

^bNo validation data available.

^cSee Dunn et al.³⁵ and Tolle et al.³⁶ for validation data.

utilized tools (Tables 6 and 7).²⁵ Moreover, panel members were aware of additional tools, developed organically at individual palliative care programs to meet the need for documentation of impact, which, although not formally evaluated, had good face validity.³³ It was decided to include some of these lesser-known tools as examples, but specifically noting which tools lacked formal validation data. None of the validated or un-validated tools listed are intended as a recommendation that these represent the “best” tools; readers are encouraged to review websites that provide more extensive information about the various measurement tools.^{27–29,33,34}

The last issue for discussion concerned the frequency of data collection and analysis. For optimal patient care, with what frequency should clinical and customer data be prospectively recorded? For clinical data, the answer is dependent on the patients’ condition and the nature of the consultation question. For example, consultation for management of post-herpetic neuralgia is unlikely to need a goal of care discussion. However, documentation of frequent assessment for distressing physical and emotional symptoms is appropriate in all patients. The panel agreed that an initial comprehensive symptom assessment, followed by at least

TABLE 7. EXAMPLES OF TOOLS TO MEASURE CUSTOMER SATISFACTION

Patient/Family Satisfaction^a
FAMCARE SCALE www.npcrc.org/resources/resources_show.htm?doc_id=376172
Family Satisfaction Tool (Massachusetts General Hospital)^b www.capc.org/tools-for-palliative-care-programs/measurement/
Family Satisfaction Survey (Mercy Health Partners, Supportive Care Coalition)^b www.supportivecarecoalition.org/NR/rdonlyres/1F8023E8-6833-4C03-8560-7825787AF559/0/familysatisfaction.pdf
Family Assessment of Treatment at End-of-Life (FATE-S-VA)^c www.caringforveterans.org/
Provider Satisfaction
Professional/Clinician Satisfaction (Fairview)^b www.capc.org/tools-for-palliative-care-programs/measurement/
Physician Satisfaction with Clinical Care Services (Dana Farber Cancer Institute)^b www.capc.org/tools-for-palliative-care-programs/measurement/

^aSee Carolinas Center for Medical Excellence²⁵ for validation data.

^bNo validation data available.

^cSee Casarett et al.²⁶ for validation data.

daily reassessment for moderate to severe symptoms, along with a comprehensive reassessment every three days, is a reasonable standard for inpatient palliative care services (Table 2). When the nature of the patient’s problem merits a goal of care discussion, this should be thoroughly documented as described (Table 3). The same idea of case-specific documentation applies to patient/family support and coordination of transitions across care sites (Tables 4 and 5).

For data on customer satisfaction, data can be collected prospectively but this would pose a large administrative burden on programs and is not recommended. An alternative is to use a sampling process. For a new program working to establish their credibility, it may be important to collect a data sample every 3–6 months, while for an established program, collection and analysis of a data obtained every few years may be sufficient. For example, a new program may choose to distribute a satisfaction survey to all referring clinicians over a 2-week period, once each quarter, during the first year of operation. This same principle of sampling applies when considering how often to audit charts for the clinical documentation recommendations in this report (Tables 2–5). Each palliative care program will need to decide an optimal frequency to meet the needs of the clinical team and other nonclinical stakeholders. For example, an established program may decide that to adequately demonstrate quality work to administrators, 10 patient charts should be reviewed every quarter.

Summary

The list of metrics included in this report is not meant to be exhaustive, but represents the minimum information that the panel believes all hospital palliative care programs should be documenting and measuring, with a frequency that meets

the needs of both the clinical care team and key nonclinical stakeholders.

The panel recognizes that continued research is needed to further define important elements of data collection that link processes of care to clinical outcomes, using validated and easy to administer tools. The panel is aware that all the elements listed in this report may not be currently in place, even in well established programs. However, to fulfill the philosophy and mission of palliative care, we believe that programs should strive to develop systems of practice that incorporate all of the listed elements. Furthermore, this report is not meant to discourage programs from capturing additional data as requested by hospital administrators, or that the program director believes would be of use in helping to sustain/grow an individual program.

Collecting and analyzing program operational data is critical for all hospital palliative care programs if we are to work toward the time when all patients in the United States with serious and complex illness can reliably access quality palliative care in their communities. The Center to Advance Palliative Care is committed to helping hospices and hospitals sustain and strengthen their palliative care programs through the kind of standardization represented by the process of routine, objective and verifiable data analyses.

Author Disclosure Statement

No competing financial interests exist.

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