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VOLUME 24 · NUMBER 30 · OCTOBER 20 2006

JOURNAL OF CLINICAL ONCOLOGY

REVIEW ARTICLE

Quality Measures for Symptoms and Advance Care Planning in Cancer: A Systematic Review

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Submitted March 31, 2006; accepted August 9, 2006.

Supported by a Veterans Affairs Health Services Research and Development Research Career Development Award (K.A.L.); National Cancer Institute K-08 (S.D.); and the Agency for Healthcare Quality and Research.

Presented at the February 2006 meeting of the American Academy of Hospice and Palliative Medicine, Nashville, TN, February 8-11, 2006.

Authors' disclosures of potential conflicts of interest and author contributions are found at the end of this article.

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0732-183X/06/2430-4933/$20.00

DOI: 10.1200/JCO.2006.06.8650

ABSTRACT

Purpose
Measuring quality of care for symptom management and ascertaining patient goals offers an important step toward improving palliative cancer management. This study was designed to identify systematically the quality measures and the evidence to support their use in pain, dyspnea, depression, and advance care planning (ACP), and to identify research gaps.

Methods
English-language documents were selected from MEDLINE, Cumulative Index to Nursing and Allied Health, PsycINFO (1995 to 2005); Internet-based searches; and contact with measure developers. We used terms for each domain to select studies throughout the cancer care continuum. We included measures that expressed a normative relationship to quality, specified the target population, and specified the indicated care. Dual data review and abstraction was performed by palliative care researchers describing populations, testing, and attributes for each measure.

Results
A total of 4,599 of 5,182 titles were excluded at abstract review. Of 537 remaining articles, 19 contained measures for ACP, six contained measures for depression, five contained measures for dyspnea, and 20 contained measures for pain. We identified 10 relevant measure sets that included 36 fully specified or fielded measures and 14 additional measures (16 for pain, five for dyspnea, four for depression, and 25 for ACP). Most measures were unpublished, and few had been tested in a cancer population. We were unable to describe the specifications of all measures fully and did not search for measures for pain and depression that were not cancer specific.

Conclusion
Measures are available for assessing quality and guiding improvement in palliative cancer care. Existing measures are weighted toward ACP, and more nonpain symptom measures are needed. Additional testing is needed before the measures are used for accountability, and basic research is required to address measurement when self-report is impaired.

J Clin Oncol 24:4933-4938. © 2006 by American Society of Clinical Oncology

INTRODUCTION

Cancer and its sequelae have a tremendous impact on patients, caregivers, and the health care system. About 9.6 million people in the United States were living with a cancer diagnosis in 2000, and cancer claimed 554,643 lives in 2003.[1,2] Both care and expenditures are concentrated disproportionately at the end of life, with approximately 30% to 35% of expenditures in the final year.[3] Quality of life is an important consideration for patients, and symptom management and anticipatory concerns about the impact of disease (such as might be addressed in comprehensive care planning) have an important impact on well-being.[4]

As concerns about the quality of life grow, supportive or palliative care is an increasingly integral concern.[5] Such care focuses on symptoms, the psychosocial context, clarifying patient goals, and supporting caregivers. Such approaches can ameliorate many debilitating consequences of cancer, regardless of stage.[6-8] Early diagnosis and effective treatment are extending the experience of cancer, making such principles more important. Palliative care programs are growing rapidly, and more than 50% of Medicare decedents with cancer were served by hospice in 1998.[9,10]

Pain, dyspnea, and depression are common and important concerns for patients and families.[11] Advance care planning (ACP) is relevant to all phases of cancer, given that difficult treatments may be used and effective communication is important to cancer patients and their caregivers.[12,13] Symptom management and ACP may be addressed

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inadequately, despite research that has begun to identify effective symptom and care planning interventions.[14]

We therefore conducted a systematic review to address the following questions. What quality-of-care measures are available and what evidence supports those measures to assess pain, depression, dyspnea, and ACP for patients with cancer? What gaps in knowledge about quality measurement are evident from the currently available literature, including absence of measures or measures lacking evidence of their scientific soundness, whether for the population of cancer patients as a whole or for specific subpopulations?

METHODS

Literature Search and Selection

We searched MEDLINE, Cumulative Index to Nursing and Allied Health, and PsycINFO for English-language literature (January 1995 to February 2005) using terms for pain, dyspnea, depression, and ACP combined with cancer, quality assessment or improvement, and palliative care. Although our review addressed cancer care, we believed evidence in the domain of ACP would be broadly generalizable to cancer. Our experience suggested that there might be little evidence for quality measures for dyspnea compared with pain and depression.[15] Therefore, our searches for ACP and dyspnea measures encompassed all conditions and were not restricted to cancer. We also used prespecified terms to search the Internet in February and March 2005 for evidence-based standards or quality measures that had been developed by health care organizations. We contacted directly the developers of all measures or measure sets we identified and sought information on experience with specific indicators.

Study Selection and Abstraction

Six trained reviewers with clinical backgrounds in internal medicine and nursing conducted study selection.[15] We applied the following criteria at the title/abstract and article screening phases. Studies or Internet documents were accepted if they contained either indicators or measures. An indicator was defined as a descriptive statement with a normative relationship to quality that includes a numerator and denominator and that is expressed as a measurable standard. A measure is an indicator fully specified for measurement including data elements, data collection approach, data sources, analysis, and presentation.[16] We defined any indicator generally as a measure if it had been fully specified previously, whether or not it had been tested in the field.

Studies or Internet documents were excluded if they were non-Western, were published in a non-English language, covered a topic other than the focus of our review, or only addressed specific types of cancer and/or processes of care that were not generalizable across the most common cancer conditions (eg, particular pain syndromes for tumor subtypes). For the domains of pain and depression, some measures or indicators were developed for populations (eg, hospice) that generally include cancer patients, although the development or field testing for these indicators may not have explicitly included cancer. We did not exclude these documents.

After joint title/abstract review, reviewers were trained on piloted forms used for detailed review of published articles and Internet documents. Articles accepted at the screening stage were abstracted using standardized forms. Some documents only described indicator or measure development, whereas others described testing or use in an actual population. We abstracted detailed information about each indicator or measure, including its target population, applicable setting, phase of illness, and information relevant to its use.

Analysis

We organized the review around fundamental domains of symptom management: assessment, treatment, and follow-up. Assessment includes all activities related to evaluating the presence of a symptom. Treatment includes all subsequent activities related to symptom mitigation. Follow-up includes reassessment and/or re-treatment. We organized ACP around these processes for clarity although in this case the task of assessment is to evaluate goals and preferences, the task of treatment is the application of advance care plans, and the task of follow-up refers to care plan implementation. Knowledge gaps were identified by comparing our findings with processes of symptom management, group discussion, and expert consultation.

Role of the Funding Sources

This contract was funded by the Agency for Healthcare Research and Quality and its federal partners (Centers for Disease Control, Center for Medicare and Medicaid Services, National Cancer Institute) to support the work of the National Quality Forum. Representatives of the sponsors and National Quality Forum participated in the initial design of the study, reviewing interim results, and in reviewing this report before academic publication. Additional methodologic details are available at http://www.ahrq.gov/downloads/pub/evidence/pdf/eolcanqm/eolcanqm.pdf.

RESULTS

We identified 5,187 titles from all sources, of which 537 were retained after abstract review. These 537 articles included 373 that were excluded after they were found to contain no indicators or measures, 113 that were excluded because the topic was outside of our domains of interest, eight that were excluded because the topic was other than cancer, five that were excluded because they were guidelines without methods, six that were excluded because they were non-Western reports, and six that were excluded because of other reasons (Fig 1).

We identified 10 sets of measures and indicators for evaluating palliative cancer care, most of which have not been described or which were described incompletely in the literature. These measurement sets included QA Tools, Assessing Care of Vulnerable Elders (ACOVE), University Health System Consortium (UHC), VHA, National Hospice and Palliative Care Organization (NHPCO), Cancer Care Nova Scotia, Cancer Care Ontario, Georgia Cancer Coalition, the American Society of Clinical Oncology Quality Oncology Practice Initiative, and the Dana-Farber measure set.

We obtained supplemental information on attributes and experience with these tools from all developers, with the exception of the Georgia Cancer Coalition, which we were unsuccessful in contacting. These measurement sets contained 11 measures and five indicators for

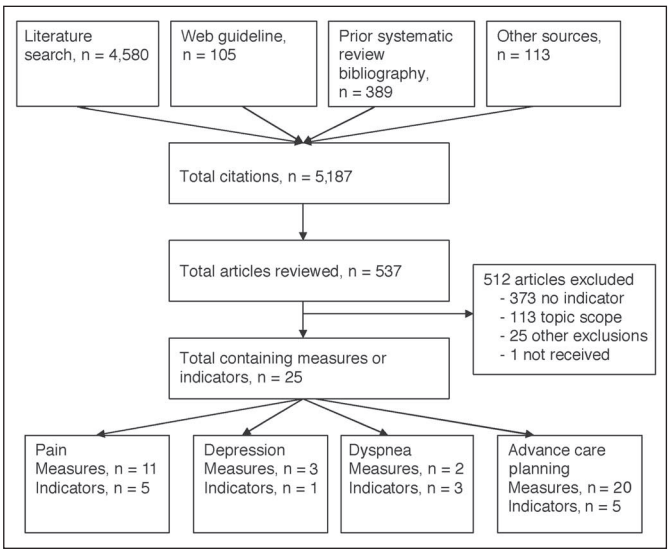

Fig 1. Literature flow.

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pain, two measures and three indicators for dyspnea, three measures and one indicator for depression, and 24 measures and 11 indicators for ACP. Measures and indicators are summarized in Table 1.

Pain Measures and Indicators

Pain measures and indicators addressed assessment (five measures, two indicators) with numeric or nonspecific scales; treatment (two measures, two indicators) including timely intervention, adverse effect/constipation prophylaxis, and radiotherapy; and follow-up (four measures, one indicator) including timely relief, satisfaction, and degree of relief (Appendix Table A1, online only). Cancer pain assessment measures and indicators addressed routine pain assessment using numeric or nonspecific scales in inpatient, intensive care, outpatient, and unspecified settings. Regarding pain assessment measures, experience is reported only with UHC and VHA measures.[17,18] A relatively high number of eligible patients met UHC criteria for regular assessment (mean, 96%) and use of a numeric pain scale (mean, 85%). VHA evaluated a measure of more frequent assessment (every 4 hours) in an intensive care unit (ICU) setting. This measure is one of the few evaluated in the context of a quality-improvement intervention in which the proportion of nursing intervals in which pain scores were measured increased from 42% to 94%, and was associated with a decrease in pain scored ≥ 3 (on a 10-point scale) from 41% to 6%.[17]

Regarding measures of pain treatment and follow-up, experience is available for measures of prophylaxis of adverse effects and timely pain care. UHC's data on regular prophylaxis of opioid-induced con-

Table 1. Cancer Quality Indicators and Measures Summary

Domain (No. of indicators or measures identified)	Aspects Addressed by Quality Indicators and Measures	Summary of Experience With Measurement
Pain		
Indicators (n = 5)	Presence of pain assessed for outpatients on regular basis; routine pain assessment during last 3 days of life; use of single-dose radiotherapy for bone metastasis to minimize radiotherapy burden, referral for radiation therapy among patients with bone metastasis	N/A
Measures (n = 11)	Presence of pain assessed for inpatients and outpatients on a timely and regular basis, use of a numeric scale for pain assessment; change in pain management in timely fashion among outpatients with uncontrolled pain (24 hours) and among hospice patients (48 hours); achievement of pain NRS $<$ 3 among ICU patients, pain relief or reduction to NRS $\leq$3 among inpatients within 48 hours; use of a bowel regimen for routine adverse effect prophylaxis with opioids; satisfaction with pain management	Shorter intervals (as frequently as 4 hours) for assessment and responsive pain treatment may be better, especially in the inpatient setting;[17] routine bowel prophylaxis was evaluated as a quality measure in one study, and with good distributional properties[18]
Dyspnea		
Indicators (n = 3)	Routine sedative and opiate use with ventilator withdrawal; routine dyspnea assessment and treatment in last week of life; therapy with oxygen among hypoxemic patients	N/A
Measures (n = 2)	Routine inpatient assessment of dyspnea with a numeric rating scale, relief or reduction to $<$ 3 on NRS within 48 hours	Only one study examined the use of these measures[18]
Depression		
Indicators (n = 1)	Routine spiritual assessment in expected dying	N/A
Measures (n = 3)	Routine assessment of psychosocial well-being among inpatients, routine assessment and treatment of depression among recently diagnosed cancer patients	Two studies (one inpatient, one outpatient) found that that only approximately 25% of health care encounters met these standards[18,19]
Advance care planning		
Indicators (n = 14)	Routine patient-family-provider communication in ICU; routine identification of a surrogate and care preferences; consistency of care delivered with documented preferences	N/A
Measures (n = 36)	Routine outpatient and inpatient documentation of surrogate and specific care preferences, routine family conferences among hospitalized patients, routine participation of decisionally capable patients in treatment decision making, routine documentation of care preferences across venues; consistency of care delivered with documented preferences; late life (30 days) hospital, ICU, new chemotherapy, emergency department, and hospice use, family report of safe dying in hospice; and site of death	One study that examined standards for advance care planning found that most encounters did not meet many of these standards (http://www.rand.org/publications/RB/RB4545-1).[19] Routine family conferencing may be an excellent metric for guiding quality improvement,[18] given that it may require complex organizational change to achieve. Administrative data-derived use metrics do not account for preferences, although they highlight important variation[20,21]

Abbreviations: N/A, not applicable; NRS, numeric rating scale; ICU, intensive care unit.

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stipation indicated a mean of 59% (median, 59%; range, 20% to 93%) of patients who were administered opioids were provided with a prophylactic bowel regimen.[18] Measures of pain follow-up included the NHPCO's timely treatment of pain in hospice.[22-25] The VHA reported on a measure of effective treatment of pain in the ICU, which was evaluated in the context of a quality-improvement intervention.[17] Cancer Care Ontario instituted a measure of satisfaction with pain treatment among outpatients with cancer that is the only measure known to be in ongoing use. Seventy percent of patients reported complete satisfaction and 25% reported partial satisfaction with pain treatment. Reports of no satisfaction with pain treatment varied from 2% to 8% across provincial sites.[23] Previous studies have noted ceiling effects for pain satisfaction.[15]

Dyspnea Measures and Indicators

Dyspnea measures and indicators addressed routine assessment (one measure) with a numeric scale; treatment (three indicators) that included any treatment, terminal treatment, and addressing hypoxia; and follow-up (one measure) addressing timely relief (Appendix Table A2, online only). Only UHC reported field experience with measures for dyspnea, and the UHC experience may not be generalizable. UHC reported that a surprising mean of 91% (median, 95%; range, 53% to 100%) of eligible patients were assessed for dyspnea in their facility cohort using a numeric scale. Sixty-two percent of all patients reported dyspnea, and 77% of cancer patients reported relief or reduction of dyspnea.[18] Reliability and validity data, and information on feasibility are lacking for these measures and indicators, and none have been used for quality improvement or are in active use.

Depression Measures and Indicators

Depression measures and indicators addressed assessment (one measure, one indicator) including psychosocial and spiritual assessment; and treatment (two measures) including regular assessment or treatment (Appendix Table A3, online only). Only UHC has been tested in the field measures in a relevant population. The one UHC measure that evaluated routine psychosocial assessment found that only 25% of eligible patients (median, 17%; range, 0% to 95%) met criteria.[18] Data on reliability and validity, and information on feasibility are lacking for these measures and indicators, and none have been used for quality improvement or are in active use.

ACP Measures and Indicators

ACP measures and indicators addressed assessment (eight measures, four indicators) including surrogate identification, preference evaluation, patient/family participation, and timely planning; ACP application (two measures) addressed documentation across venues and evaluation of specific life-sustaining preferences; and ACP follow-up (10 measures, one indicator) addressed preference-treatment consistency, hospice admission, and late-life use of hospital or intensive care settings, emergency care, and chemotherapy (Appendix Table A4, online only).

Documentation of surrogacy is widely acknowledged as an important tool for clinicians. Two ACOVE measures addressed this issue and only 4% of eligible outpatient charts and 25% of 20 eligible inpatient charts in ACOVE's community-based sample passed the aforementioned criteria.[19] With regard to regular assessment of preferences, two ACOVE measures addressed this issue among inpatients with dementia and ICU admissions, and one NHPCO measure addressed preference determination in hospice. A convenience sample of NHPCO respondents reported that 97% of eligible patients' preferences were appropriately assessed.[22-25] Measures were assessable in only a small number of patients in ACOVE's community-based sample (two patients for the dementia measure; six patients for the ICU measure).[19]

Two measures addressed participation in treatment decisions or care plans. An ACOVE measure that addressed patient participation in decisions to limit care found that seven of the 10 eligible patients met this criterion.[19] A UHC measure that addressed family meetings found that a mean of only 39% (median, 41%; range, 0% to 93%) of a cohort met the criterion of regular patient-family meetings within a week of admission to discuss preferences and/or disposition. UHC's measure set also addressed timely and effective discharge planning (within 4 days of admission) and 53% (median, 53%; range, 18% to 94%) of patients met this criterion, including 62% of cancer patients.[18] Two ACOVE measures addressed the application or documentation and use of measures. Only two of eight eligible patients met the criterion that care plans were transferred with a patient to a secondary setting when such plans were documented in a primary setting. Regarding documentation of specific life-sustaining preferences, if a patient described limitations in life-sustaining preferences in an interview, only 12% of 238 eligible patients were documented in the medical record.[19]

A large number of measures addressed the issue of use of care. We included such measures because most of the literature on ACP has focused on avoiding certain treatment or use outcomes.[15] Of measures identified, only one of these (ACOVE) addressed consistency of eventual treatment with expressed preferences. Only two patients in ACOVE's community-based sample were appropriate for this measure.[19] Eight measures addressed various measures of use (late-life hospital use, ICU use, emergency care, chemotherapy, hospice, and site of death).[20,21,26,27] Of these indicators, it is notable that Cancer Care Ontario has implemented and Cancer Care Nova Scotia is actively pursuing additional development and implementation. Although none of these measures adjust for preferences, they address widespread concern about inappropriate use of care in late life.[28] Most address overuse, but several address underuse of hospice or palliative services.

DISCUSSION

We identified many measures or indicators for addressing pain, dyspnea, depression, and ACP. Most were developed recently, and few of them have been tested specifically in a cancer population or across the full chronologic trajectory of cancer care. They all address outcomes that have varying degrees of support as normative standards, although utilization based indicators probably are most controversial in that regard. Our systematic review did not uncover much information about how well these measures promote quality improvement because there has been little investment in deploying these measures.

Substantial indirect evidence supports pain measures, largely in the form of guideline implementation that has addressed either the WHO pain ladder,[29-33] Agency for Health Care Policy and Research guideline for the treatment of cancer pain,[34-36] American Pain Society guidelines,[37] or quality improvement programs that instituted many elements of these guidelines.[38-41] A nonsystematic review that summarized many quality improvement studies for pain found that 90% of them reported using a measure of pain intensity.[42] For example, one

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study that instituted routine assessment of pain intensity found that it was carried out on 75% of patients during first 5 months, but then declined markedly among both nurses and physicians,[43] underscoring the need for sustained monitoring.

Among the major gaps in palliative cancer quality measurement is the failure to address patients' often impaired ability to report their own symptoms and preferences. This can be due to temporary (eg, delirium) or durable (eg, dementia, brain metastasis) factors. Delirium has been reported among 18% to 50% of cancer patients, and rates may be even higher in the ICU or nursing homes.[44] The palliative care needs of these populations are certainly profound; of 190,976 cancer cases in 1999 in US nursing homes, 51% who survived more than one assessment reported persistent pain, 25% of all patients were using oxygen, only 45% had do not resuscitate orders, and only 25% of those designated terminally ill received hospice services.[45]

A closely related issue is the lack of consensus about what constitutes the purview of cancer palliative care. There were frequent discussions in the selected articles regarding the definition of end of life; most definitions went beyond the restriction to the imminently dying. Many of the measures or indicators we identified define end of life retrospectively (eg, last 6 months, 2 weeks, or 3 days). This does not provide guidance on important clinical services such as pain prevention or the timing of ACP. The ACOVE indicators approach this goal by identifying vulnerable community elders for which the identification and documentation of life-sustaining treatment decisions may be most appropriate. Diagnoses or sentinel events may assist in specifying palliative measures.[46]

Our review provides a limited description of the specification of some measures and indicators, and that may affect measure feasibility and performance. For example, descriptions do not necessarily address instrumentation (eg, the approach used to measure pain on a scale of zero to 10). One might consider it a limitation that conditions other than cancer were not included in searches for the topics of pain and depression. The ability to use tools developed for one condition and apply them to another rests on the assumptions that management is similar and that there are no particular measurement challenges in translating across conditions. These are empirically testable propositions that should be evaluated.

Applying the most well-developed palliative care measures would foster important progress. Many measures may be useful now for local quality assessment and improvement. However, robust information about the validity, reliability, ability to discriminate performance, and responsiveness to change of these measures is needed. Implementations are needed to evaluate specific measures in various settings (home, nursing home, hospital, and hospice), and clinical contexts (phase of illness and treatment). Data sources may require modification to track metrics such as the timing of medication or other treatments.

Selection of optimal measures requires information about the current performance of any particular system, and the usefulness of thresholds for particular measures also requires empiric examination. Before widespread use for accountability, providers must consider the cost and feasibility of data collection; providers also must be assured that measures are low risk for gaming and that they can provide timely, operationally relevant feedback.[16] Because almost all late-life care is a federal responsibility, government leadership and funding for such efforts will be required to make progress in palliative quality measurement.

In conclusion, palliative care represents an important but insufficiently acknowledged dimension of quality measurement. Although many unpublished studies exist in the medical literature, robust work is identifying potentially useful tools for promoting high-quality palliative cancer care. Priorities for future research include testing in relevant populations and addressing impaired self-report. An important priority is to build an evidence base so that patients and family members living with cancer can be assured that the health care system is appropriately accountable for palliation, as it is for prevention, diagnosis, and treatment.

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Acknowledgment

We thank Susan Chen, Rena Garland, and Roberta Shanman for their assistance with this study.

Appendix

The Appendix is included in the full-text version of this article, available online at www.jco.org. It is not included in the PDF version (via Adobe® Reader®).

Authors' Disclosures of Potential Conflicts of Interest

The authors indicated no potential conflicts of interest.

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