

Effective Health Care Program Research Reports

Number 25

A Review of Quality of Care Evaluation for the Palliation of Dyspnea

Richard A. Mularski, M.D., M.S.H.S., M.C.R.

Margaret L. Campbell, Ph.D., R.N., FAAN

Steven M. Asch, M.D., M.P.H.

Bryce B. Reeve, Ph.D.

Ethan Basch, M.D., M.Sc.

Terri L. Maxwell, Ph.D., APRN, BC-PCM

J. Russell Hoverman, M.D., Ph.D.

Joanne Cuneo, R.N., M.B.A.

Steve B. Clauser, Ph.D.

Claire Snyder, M.H.S., Ph.D.

Hsien Seow, Ph.D.

Albert W. Wu, M.D., M.P.H.

Sydney Dy, M.D., M.Sc.

Research from the Developing Evidence to Inform Decisions about Effectiveness (DEcIDE) Network



Agency for Healthcare Research and Quality
Advancing Excellence in Health Care • www.ahrq.gov

April 2010

The DEcIDE (Developing Evidence to Inform Decisions about Effectiveness) network is part of AHRQ's Effective Health Care Program. It is a collaborative network of research centers that support the rapid development of new scientific information and analytic tools. The DEcIDE network assists health care providers, patients, and policymakers seeking unbiased information about the outcomes, clinical effectiveness, safety, and appropriateness of health care items and services, particularly prescription medications and medical devices.

This report is based on research conducted by the Johns Hopkins University DEcIDE (Developing Evidence to Inform Decisions about Effectiveness) Center under contract to the Agency for Healthcare Research and Quality (AHRQ), Rockville, MD (Contract No. 290-2005-0034I) with funding from the National Cancer Institute. The AHRQ Task Order Officer for this project was William Lawrence, M.D., M.S.

The findings and conclusions in this document are those of the authors, who are responsible for its contents; the findings and conclusions do not necessarily represent the views of AHRQ or the National Cancer Institute. Therefore, no statement in this report should be construed as an official position of AHRQ, the National Cancer Institute, or the U.S. Department of Health and Human Services.

None of the authors has a financial interest in any of the products discussed in this report.

This report has been published in edited form: Mularski RA, Campbell ML, Asch SM, et al. A review of quality of care evaluation for the palliation of dyspnea. *Am J Respir Crit Care Med* 2010 Mar 15;181(6):534-8. E-pub 2010 Jan 7.

Suggested citation:

Mularski RA, Campbell ML, Asch SM, Reeve BB, Basch E, Maxwell TL, Hoverman JR, Cuny J, Clauser SB, Snyder C, Seow H, Wu AW, Dy S. A review of quality of care evaluation for the palliation of dyspnea. Effective Health Care Program Research Report No. 25. (Prepared by Johns Hopkins University DEcIDE Center under Contract No. 290-2005-0034I). Rockville, MD: Agency for Healthcare Research and Quality. April 2010. Available at: <http://effectivehealthcare.ahrq.gov/reports/final.cfm>.

Contents

Evaluation of the Quality of Palliative Dyspnea Care	1
Part 1: Quality Measures of the Palliative Dyspnea Care Experience.....	1
Part 2: Measurement Instruments for the Clinical Assessment of Dyspnea.....	3
Conclusions and Recommendations	4
Acknowledgments.....	5
References.....	6
Abbreviations	8
Table	9

Author affiliations:

Richard A. Mularski, M.D., M.S.H.S., M.C.R.^a

Margaret L. Campbell, Ph.D., R.N., FAAN^b

Steven M. Asch, M.D., M.P.H.^c

Bryce B. Reeve, Ph.D.^d

Ethan Basch, M.D., M.Sc.^e

Terri L. Maxwell, Ph.D., APRN, BC-PCM^f

J. Russell Hoverman, M.D., Ph.D.^g

Joanne Cunny, R.N., M.B.A.^h

Steve B. Clauser, Ph.D.^d

Claire Snyder, M.H.S., Ph.D.ⁱ

Hsien Seow, Ph.D.ⁱ

Albert W. Wu, M.D., M.P.H.ⁱ

Sydney Dy, M.D., M.Sc.ⁱ

^aThe Center for Health Research, Kaiser Permanente Northwest, Portland, OR

^bDetroit Receiving Hospital, Center for Health Research, Wayne State University, Detroit, MI

^cVA Greater Los Angeles Healthcare System, Department of Medicine, David Geffen School of Medicine UCLA, Los Angeles, CA

^dNational Cancer Institute, Bethesda, MD

^eHealth Outcomes Group, Memorial Sloan-Kettering Cancer Center, New York, NY

^fexcelleRx, Inc., an Omnicare Company, Philadelphia, PA

^gTexas Oncology, P.A., Dallas Texas

^hHealthSystem Consortium, Oak Brook, IL

ⁱJohns Hopkins Bloomberg School of Public Health, Baltimore, MD

Abstract

Assessment and management of dyspnea has emerged as a priority topic for quality evaluation and improvement. Evaluating dyspnea quality of care requires valid, reliable, and responsive measures of the care provided to patients across settings and diseases. As part of an AHRQ Symposium, we reviewed quality of care measures for dyspnea by compiling quality measures identified in systematic searches and reviews. Systematic reviews identified only 3 existing quality measurement sets that included quality measures for dyspnea care. The existing dyspnea quality measures reported by retrospective evaluations of care assess only 4 aspects: dyspnea assessment within 48 hours of hospital admission, use of objective scales to rate dyspnea severity, identification of management plans, and evidence of dyspnea reduction.

To begin to improve care, clinicians need to assess and regularly document patient's experiences of dyspnea. There is no consensus on how dyspnea should be characterized for quality measurement and although over 40 tools exist to assess dyspnea, no rating scale or instrument is ideal for palliative care. The panel recommended that dyspnea assessment should include a measure of intensity and some inquiry into the associated bother or distress experienced by the patient. A simple question into the presence or absence of dyspnea would be unlikely to help guide therapy, as complete relief of dyspnea in advanced disease would not be anticipated. Additional knowledge gaps include standards for clinical dyspnea care, assessment in the cognitively impaired, and evaluation of effectiveness of dyspnea care for patients with advanced disease.

Evaluation of the Quality of Palliative Dyspnea Care

Despite the commonness and debilitation of dyspnea, clinical assessment and palliation of dyspnea is sporadic and few quality measures exist to guide dyspnea care improvement.¹⁻¹⁴ Improving dyspnea care requires evaluation with quality measures of the care provided within the scope of palliation. The World Health Organization (WHO) defines palliative care as "...an approach that improves the quality of life of patients ... through the prevention and relief of suffering by means of ... assessment and treatment of pain and other problems, physical, psychosocial and spiritual."² As clinical practice guidelines stress, symptom assessment and treatment should be comprehensive and patient-centered.^{13,15}

Optimizing care for dyspnea requires systematized and rigorous methods for evaluating relevant clinical processes and outcomes of care.^{1-14,16-22} As part of work to review palliative measures and provide guidance on palliative care quality measurement for an Agency for Healthcare Research and Quality (AHRQ) task order, we compiled dyspnea quality indicators and measures from prior systematic reviews that are summarized in the first part of this article.^{1,7,16,18} In the second part of our review we summarize assessment instruments for clinical dyspnea care. Lastly, we review the key recommendations of the Symposium members. A table is provided with key definitions of constructs used in this paper (see table); we adhere to a convention of terms 'evaluation' and 'measure' for discussing quality of care concepts in part one and use 'assessment' and 'dyspnea instruments' for clinical care discussion in part two.

Part 1: Quality Measures of the Palliative Dyspnea Care Experience

A dyspnea quality measure review was performed under contract from the AHRQ, Developing Evidence to Inform Decisions about Effectiveness (DECIDE) Network, with support from the National Cancer Institute. As part of the Symposium on Developing a Framework to Assess Cancer Quality Indicators for End-of-Life Care held in Baltimore, MD, on April 28, 2008,^{7,18} we sought to identify any publicly available quality indicators or measures in the domains of processes (what healthcare provider do) and outcomes (patient-level effects of healthcare) for dyspnea (see table for clarifications of quality terms). The authors used a prior systematic review of over 5000 titles in Western literature for quality measures of symptom management across diseases and settings, searching English language documents from Medline, CINAHL, PsychInfo from 1995-2005,¹⁶ augmented with revised systematic reviews, Internet-based searches, and contact with quality measure developers.^{1,7,10-12,18-20}

Assessment of dyspnea is recognized as an important priority for healthcare quality.^{8,21} However, the AHRQ group only identified 5 operationalized quality measures, 14 quality indicators, and a number of other quality statements about recommended care related to dyspnea. Most dyspnea indicators address general conceptual areas of routine assessment (suggesting regular use of a quantitative rating with a numeric scale, but not specifying any particular tool), treatment in broad terms including diagnosis or management of underlying etiology or administration of opiates, and exploration of timely relief of dyspnea in follow-up. Reliability and validity data and information on feasibility are lacking for these measures and indicators, and none had evidence of being used for quality improvement. None of the identified measures reported interrater reliability or other psychometric properties.

In this section, we review the measures identified. Only the University Health Consortium (UHC) Palliative Care Benchmarking Project²² has reported field experience with measures for dyspnea. Using retrospective survey of medical records for hospitalized patients designed as a benchmarking and comparative performance assessment, institutional representatives report 4 patient-based aspects relating to dyspnea:

1. Dyspnea assessed within 48 hours of hospital admission
2. Use of an objective scale (not specified) for documentation of severity of dyspnea
3. Dyspnea plan established with patients/families within 48 hours
4. Dyspnea relief/reduction achieved within 48 hours of onset

In 2004, UHC reported a baseline mean of 91% (median 95%, range 53-100%) of eligible cases were assessed for dyspnea in their reporting facilities within the first 48 hours. These assessments may have included dichotomous identification (yes/no) for the presence of dyspnea, a numerical intensity rating such as a 0-5 or 0-10 Numerical Rating Scale (NRS) or Visual Analog Scale (VAS), or descriptive severity ratings (e.g. mild, moderate, or severe). Aggregate results from 2007 reported assessment for dyspnea in 94% of medical records, but a quantitative scale for documentation of severity of dyspnea was reported in only 8.5% of the assessments.²²

Since the 2008 AHRQ Symposium, one dyspnea quality measure was submitted through the National Quality Forum (NQF) and has been operationalized and approved for use in assessing physician performance and guiding quality improvement as part of the American Medical Association, Physician Consortium for Performance Improvement (PCPI) palliative care measure set.¹⁷ The dyspnea measure evaluates the proportion of patients with advanced chronic diseases or serious life threatening illness who are screened for dyspnea and the proportion of patients found to have moderate or severe dyspnea who have a documented plan of care to manage dyspnea. No data on this measure's use, validity testing, or clinical performance as an assessment of care or ability to guide quality improvement efforts are yet available.

We also found a number of quality indicators evaluating assessment for critically ill patients, such as respiratory distress for non-ventilated patients or patient-ventilator dysynchrony for ventilated patients.^{3,14} One example from a quality measure set targeting the elderly (Assessing Care of Vulnerable Elders or ACOVE) advocated use of a quantitative rating instrument for self-reported assessment of dyspnea, but did not specify any particular scale.¹⁴ A number of other quality indicators also encourage assessment of dyspnea, e.g. a cancer recommendation that providers should evaluate for causes of new or worsening dyspnea with routine assessment of underlying causes,¹⁰ a Japanese end-of-life indicator for assessment of the presence or absence of dyspnea,²⁰ and a Palliative Care Quality Measures Project (PEACE) indicator for assessment of the percent of patients screened for shortness of breath during an admission visit.¹⁹

Lastly, we identified quality indicators for dyspnea treatment that include general statements endorsing evaluation for management plans, for evidence of therapy for specific pathophysiological or disease-specific etiologies (e.g. bronchodilator, thoracentesis, and pleurodesis), or for documentation of the use of symptomatic-focused therapies, primarily opiates.^{3,14,19,20,22}

Part 2: Measurement Instruments for the Clinical Assessment of Dyspnea

Evaluation and management of dyspnea must begin with recognizing patients at risk for dyspnea and regularly assessing the symptom experience during clinical interactions.^{2,15} Quality measures encourage use of simple and minimally burdensome instruments to assess dyspnea in advanced disease patients in the settings and situations where they receive care. As part of the Symposium, experts reviewed assessment instruments (tools clinicians can use to assess the symptom of dyspnea) and employed an informal iterative consensus approach to make recommendations to the US government.^{7,18} We review these instruments in four categories:

1. intensity ratings that quantify severity of dyspnea,
2. situational or functional assessments of the impact of dyspnea on activity and performance,
3. measures of the effect of dyspnea and/or cardiopulmonary disease on health-related quality of life (HRQoL) or health status, and
4. sets of qualitative descriptors that primarily aim to discriminate subtypes of dyspnea.

Intensity rating instruments use one-dimensional scales to assess and quantify dyspnea at a particular moment in time. These assessments may be sufficiently sensitive for initially monitoring the dyspnea experience and guiding management in advanced disease. Examples of evaluative rating scales that quantify intensity of dyspnea include Visual Analogue Scale (VAS),²³ Borg or Modified Borg Dyspnea Scale,²⁴ and numeric rating scale (NRS).²⁵

The VAS is classically a 100 mm line anchored at either end with descriptors such as “none” to “most severe” and yields a nearly continuous rating based on respondents marking a point on the line to represent their symptom experience; horizontal and vertical versions correlate well ($r = 0.97$) and have been used in therapeutic trials.^{23,26} The Borg is a 10 point category-ratio scale with descriptive terms anchoring responses and has high concordance with the VAS, being best in post-activity testing.²⁶⁻²⁸

The NRS is typically a 0 to 10 integer scale that may be anchored with descriptors such as 0 = “no shortness of breath” and 10 = “worst possible shortness of breath.”²⁵ The NRS and VAS were felt by panelists to be appropriate for clinical dyspnea assessment in chronic progressive diseases and for the bed-bound, including use in daily diary recordings, for evaluation of acute changes, and in titration of therapy. While these single item measures are quick to administer, they have the disadvantage of not being comprehensive to capture the full experience of dyspnea.

Tools in the second category, functional assessments of the impact of dyspnea on activity or situational performance, include the Oxygen Cost Diagram,²⁹ Baseline Dyspnea Index and Transition Dyspnea Index,³⁰ Modified Medical Research Council dyspnea scale (MMRC),³¹ and the University of California, San Diego, Shortness of Breath Questionnaire (SOBQ),³² among others. These multidimensional measures have varying strengths for assessing different aspects and impacts of dyspnea and correlate well to one-item intensity scales. They have the disadvantages of increased burden to administer and generally report the history or trend of dyspnea. Thus these and category 3 instruments might be better for palliative care program evaluation or episodic quality improvement research.

Measurement tools in the third category assessing the effect of dyspnea and/or cardiopulmonary disease on HRQoL and health status include the Chronic Respiratory Disease Questionnaire (CRQ),³³ the Saint George Respiratory Questionnaire (SGRQ),³⁴ Pulmonary Functional Status Scale (PFSS),³⁵ Breathing Problems Questionnaire,³⁶ the Airways Questionnaire 20 (AQ20),³⁷ the Pulmonary Functional Status and Dyspnea Questionnaire (PFSDQ),³⁸ and others. Similar to intensity and activity impact dyspnea scales, correlations among HRQoL measures are high, $r = 0.72$ to 0.82 ,³⁹ and the summary scores group well with functional status and activity impact assessment.⁴⁰ These complex tools comprehensively assess the impact on various important and valued effects of disease and are relevant for clinical research, but most are overly burdensome to patients for routine patient care. Lastly, qualitative sets of descriptors, such as the Breathing Descriptor, have utility in discriminating subtypes of dyspnea^{9,41-44} but, in the context of advanced disease where underlying causes should already be addressed with optimal medical therapy, these tools are less applicable for the goal of guiding palliative dyspnea management.

Dyspnea has been shown to coexist with other distressing symptoms such as anxiety, fatigue, pain, and nausea and relates to experiences of fear, helplessness, loss of vitality, and other troublesome feelings.^{25,45-49} A symptom such as dyspnea is a complex result of physiological derangement, neural transmission to the brain, and processing of that information in conjunction with context and prior experiences to yield a unique individual perception. Even for different levels of dyspnea intensity, the meaning of this symptom in context with a person's perspectives and preferences for care may vary greatly and suggest the clinical need to tailor management.

Standard measurement tools for dyspnea rely on the patient's ability to self-report. However, not all patients who experience dyspnea are able to reliably self-report because of impairments of consciousness or declining cognition, making them vulnerable to mis-estimation of dyspnea and over or under-treatment.⁴⁵ Symptoms such as dyspnea are ultimately only typified by the person who experiences it. However for the cognitively impaired, especially at the end of life, ethical principles support management approaches guided by other relevant sources for assessing distressing symptoms, such as family report or provider observation.^{5,9,15,46} A novel instrument, the Respiratory Distress Observation Scale (RDOS) was developed from observational studies to assess the presence and intensity of respiratory distress for patients who are unable to self-report.⁴⁸

Conclusions and Recommendations

Dyspnea quality measurement and quality improvement efforts will likely expand in future years. The current field of dyspnea quality measurement and improvement is young and most proposed dyspnea quality measures lack data on reliability, validity, and feasibility. Evaluation and management of dyspnea requires recognizing patients at risk for dyspnea and regularly assessing and characterizing the patient experience of dyspnea at clinical interactions. Although guidelines and evidence support assessment of dyspnea,^{5,6,13,15,50} research is needed to understand the most appropriate symptom assessment instruments and how these link to patient-centered priorities for intervention across settings and along the care continuum from chronic disease diagnosis to death. Evidence gaps include the lack of consensus on how dyspnea should be characterized for quality measurement, standards for clinical dyspnea care, data to guide selection of optimal assessment instruments for use in advanced disease and in the cognitively

impaired, and information on the efficacy of palliative dyspnea care for patients with advanced disease.

Two recent systematic reviews have identified over 40 instruments to assess the symptom of dyspnea,^{11,12} however no scale or tool has been shown to be optimal for palliative care.

Ideally, assessment would be performed by a simple and minimally burdensome tool that has been demonstrated to be valid, reliable, and responsive in advanced disease patients and for the settings and situations where they receive care. The Symposium panel agreed that the clinical quality imperative is for some measure of dyspnea to be regularly used to quantify the patient experience of dyspnea and be repeated to aid management. At a minimum, dyspnea assessment should include a measure of intensity and some inquiry into the associated bother or distress experienced by the patient. Inquiry into only the presence or absence of dyspnea is unlikely to help guide therapy as complete relief of dyspnea in advanced disease would not be anticipated.

The numerical rating scale and visual analogue scale are appropriate assessment tools in palliative care. The NRS might be recommended as it is easy for patients to use across healthcare settings (acute, outpatient, critical care, home, hospice), is increasingly familiar due to increased use of the pain NRS, and can be reported verbally or visually as patients become fluent with its use. For cognitively impaired patients, the RDOS is an emerging measure that may perform adequately to guide management.

Managing dyspnea involves both therapy focused at treating underlying pathophysiological derangements and providing general dyspnea palliative care for the symptom experience.^{2,6,8,13}

In individualizing the management of dyspnea, clinicians should base clinical management responses on each patient's preferences and expressed needs. For one patient, a high level of dyspnea may be tolerable, for another the same intensity rating would demand intervention. Future research should strive to better understand the best ways to measure the distress, personal interpreted experience, and medical care needs related to dyspnea evaluation and care.

Because of the many etiologies and treatment options for dyspnea, experts were unable to make recommendations for how dyspnea treatment should be operationalized into quality measures that would reliably link to improved patient outcomes. Experts recommended that, at a minimum, some re-assessment should occur, and, ideally, a management plan for addressing dyspnea should be documented. Routine documentation in the medical record and regular reassessment after therapeutic interventions with an intensity instrument is a minimal requirement to guide palliation of dyspnea and may be used as a quality marker until more sophisticated indicators are developed and tested.

Acknowledgments

We acknowledge those members of the DEcIDE Symposium dyspnea subgroup who participated in this work but did not meet criteria for authorship: Marian Grant, Mark Leenay, Lee Newcomer, Karen Pace, Bryce Reeve, and Deborah Dudgeon. We would also like to acknowledge participation by 2 authors (RAM, MLC) in the ongoing American College of Chest Physicians, Management of Dyspnea in Patients with Advanced Lung or Heart Disease Evidence-Based Clinical Practice Guidelines committee, chaired by Donald A. Mahler, MD, FCCP, that helped inform our approach to dyspnea assessment.

References

1. Lorenz KA, Lynn J, Dy S, et al. Quality measures for symptoms and advance care planning in cancer: A systematic review. *J Clin Oncol* 2006;24:4933-4938.
2. World Health Organization. World Health Organization: WHO definition of palliative care, 2005. Available at <http://www.who.int/cancer/palliative/definition/en/>. Accessed on January 12, 2006.
3. Mularski RA, Curtis JR, Billings JA, et al. Proposed quality measures for palliative care in the critically ill: A consensus from the Robert Wood Johnson Foundation Critical Care Workgroup. *Crit Care Med* 2006;34:S404-S411.
4. Smith KL, Soriano TA, Boal J. Brief communication: National quality-of-care standards in home-based primary care. *Ann Intern Med* 2007;146:188-192.
5. Carrieri-Kohlman V, Dudgeon D 2006. Multidimensional assessment of dyspnea. In Booth S and Dudgeon D, editors *Dyspnoea in advanced disease: A guide to clinical management* Oxford University Press, New York; pp. 19-38.
6. Kvale PA, Simoff M, Prakash UB. Lung cancer. Palliative care. *Chest*. 2003;123:284S-311S.
7. Seow H, Snyder CF, Shugarman LR, et al. Developing quality indicators for cancer end-of-life care: Proceedings from a national symposium. *Cancer* 2009;115(17):3820-3829.
8. The Hospice and Palliative Medicine National Consensus Guidelines. Available at: <http://www.nationalconsensusproject.org>. 2004. Accessed June 17, 2007.
9. American Thoracic Society. Dyspnea. Mechanisms, assessment, and management: A consensus statement. *Am J Respir Crit Care Med* 1999;159:321-340.
10. Lorenz KA, Dy SM, Naeim A, et al. Quality Measures for Supportive Cancer Care: The Cancer Quality-ASSIST Project. *J Pain Sympt Manage* 2009;37(6):943-964.
11. Bausewein C, Farquhar M, Booth S, et al. Measurement of breathlessness in advanced disease: a systematic review. *Respir Med* 2007;101:399-410.
12. Dorman S, Byrne A, Edwards A. Which measurement scales should we use to measure breathlessness in palliative care? A systematic review. *Palliat Med* 2007;21:177-191.
13. Lanken PN, Terry PB, Delisser HM, et al. An official American Thoracic Society clinical policy statement: palliative care for patients with respiratory diseases and critical illnesses. *Am J Respir Crit Care Med* 2008;177:912-927.
14. Lorenz K, Rosenfeld K, Wenger N. Quality indicators for palliative and end-of-life care in vulnerable elders. *J Am Geriatr Soc* 2007;55 Suppl 2:S318-S326.
15. National Consensus Project. Clinical practice guidelines for palliative care: 2004. Available at: <http://www.nationalconsensusproject.org>. Accessed October 29, 2009.
16. Lorenz KA, Lynn J, Dy SM, et al. Evidence for improving palliative care at the end of life: A systematic review. *Annals of Internal Medicine* 2008;148(2):147-159.
17. American Medical Association. Palliative and End of Life Care Physician Performance Measurement Set. Available at: <http://www.ama-assn.org/ama/no-index/physician-resources/palliative-care.shtml>. Accessed February 24, 2009.
18. Seow H, Snyder CF, Mularski RA, et al. A framework for assessing quality indicators for cancer care at the end of life. *J Pain Sympt Manage* [in press, available online September 23, 2009 at doi:10.1016/j.jpainsymman.2009.04.024].
19. Carolinas Center for Medical Excellence. Palliative care quality measurement project. Medicare quality improvement community (MedQIC-Hospice). 2008. Available at: <http://www.medqic.org>. Accessed September 4, 2009.
20. Miyashita M, Nakamura A, Morita T, et al. Identification of quality indicators of end-of-life cancer care from medical chart review using a modified Delphi method in Japan. *Am J Hosp Palliat Care* 2008;25:33-38.

21. National Priority Partnership, Palliative and End-of-Life Care. Available at: <http://www.nationalprioritiespartnership.org/PriorityDetails.aspx?id=608>. Accessed May 30, 2009.
22. Twaddle ML, Maxwell TL, Cassel JB, et al. Palliative care benchmarks from academic medical centers. *J Palliat Med* 2007;10:86-98.
23. Gift AG. Validation of a vertical visual analogue scale as a measure of clinical dyspnea. *Rehabil Nurs* 1989;14:323-325.
24. Borg GA. Psychophysical bases of perceived exertion. *Med Sci Sports Exerc* 1982;14:377-381.
25. Gift AG, Narsavage G. Validity of the numeric rating scale as a measure of dyspnea. *Am J Crit Care* 1998;7:200-204.
26. Meek PM. Measurement of dyspnea in chronic obstructive pulmonary disease: what is the tool telling you? *Chron Respir Dis* 2004;1:29-37.
27. Wilson RC, Jones PW. A comparison of the visual analogue scale and modified Borg scale for the measurement of dyspnoea during exercise. *Clin Sci* 1989;76:277-282.
28. Mahler DA, Guyatt GH, Jones PW. Clinical measurement of dyspnea. In Mahler DA, editor. *In Dyspnea* Marcel Dekker, New York; 1997. pp. 149-198.
29. McGavin CR, Artvinli M, Naoe H, et al. Dyspnoea, disability, and distance walked: comparison of estimates of exercise performance in respiratory disease. *Br Med J* 1978;2:241-243.
30. Mahler DA, Weinberg DH, Wells CK, et al. The measurement of dyspnea. Contents, interobserver agreement, and physiologic correlates of two new clinical indexes. *Chest* 1984;85:751-758.
31. Mahler DA, Wells CK. Evaluation of clinical methods for rating dyspnea. *Chest* 1988;93:580-586.
32. Eakin EG, Resnikoff PM, Prewitt LM, et al. Validation of a new dyspnea measure: the UCSD Shortness of Breath Questionnaire. University of California, San Diego. *Chest* 1998;113:619-624.
33. Guyatt GH, Berman LB, Townsend M, et al. A measure of quality of life for clinical trials in chronic lung disease. *Thorax* 1987;42:773-778.
34. Jones PW, Quirk FH, Baveystock CM, et al. A self-complete measure of health status for chronic airflow limitation. The St. George's Respiratory Questionnaire. *Am Rev Respir Dis* 1992;145:1321-1327.
35. Weaver TE, Narsavage GL, Guilfoyle MJ. The development and psychometric evaluation of the Pulmonary Functional Status Scale: an instrument to assess functional status in pulmonary disease. *J Cardiopulm Rehabil* 1998;18:105-111.
36. Hyland ME, Bott J, Singh S, et al. Domains, constructs and the development of the breathing problems questionnaire. *Qual Life Res* 1994;3:245-256.
37. Quirk FH, Jones PW. Back to basics: How many items can adequately represent health-related quality of life in airways disease? *Eur Respir Rev* 1997;7:50-52.
38. Lareau SC, Meek PM, Roos PJ. Development and testing of the modified version of the pulmonary functional status and dyspnea questionnaire (PFSDQ-M). *Heart Lung* 1998;27:159-168.
39. Hajiro T, Nishimura K, Tsukino M, et al. A comparison of the level of dyspnea vs disease severity in indicating the health-related quality of life of patients with COPD. *Chest* 1999;116:1632-1637.
40. Hajiro T, Nishimura K, Tsukino M, et al. Analysis of clinical methods used to evaluate dyspnea in patients with chronic obstructive pulmonary disease. *Am J Respir Crit Care Med* 1998;158:1185-1189.
41. Elliott MW, Adams L, Cockcroft A, et al. The language of breathlessness. Use of verbal descriptors by patients with cardiopulmonary disease. *Am Rev Respir Dis* 1991;144:826-832.
42. Mahler DA, Harver A, Lentine T, et al. Descriptors of breathlessness in cardiorespiratory diseases. *Am J Respir Crit Care Med* 1996;154:1357-1363.
43. Moy ML, Lantin ML, Harver A, et al. Language of dyspnea in assessment of patients with acute asthma treated with nebulized albuterol. *Am J Respir Crit Care Med* 1998;158:749-753.
44. Simon PM, Schwartzstein RM, Weiss JW, et al. Distinguishable types of dyspnea in patients with shortness of breath. *Am Rev Respir Dis* 1990;142:1009-1014.

45. Cassell EJ, Leon AC, Kaufman SG. Preliminary evidence of impaired thinking in sick patients. *Ann Intern Med* 2001;134:1120-1123.
46. Lorenz K, Lynn J, Dy S, et al. Cancer care quality measures: Symptoms and end-of-life care. *Summary, evidence report/technology assessment: Number 137*. AHRQ Publication No. 06-E001, May 2006. AHRQ, Rockville, MD.
47. Campbell ML. Fear and pulmonary stress behaviors to an asphyxial threat across cognitive states. *Res Nurs Health* 2007;30:572-583.
48. Campbell ML. Psychometric testing of a respiratory distress observation scale (RDOS). *J Palliat Med* 2008;11:44-50.
49. Desbiens NA, Mueller-Rizner N, Connors AF, et al. The relationship of nausea and dyspnea to pain in seriously ill patients. *Pain* 1997;71:149-156.
50. Celli BR, MacNee W. Standards for the diagnosis and treatment of patients with COPD: a summary of the ATS/ERS position paper. *Eur Respir J* 2004;23:932-946.

Abbreviations

AHRQ = Agency for Healthcare Research and Quality
ACOVE = Assessing Care of Vulnerable Elders
AHRQ = Agency for Healthcare Research and Quality
CER = Comparative effectiveness research
CMS = Centers for Medicare and Medicaid Services
DEcIDE = Developing Evidence to Inform Decisions about Effectiveness (an AHRQ network)
HEDIS = Healthcare Effectiveness Data and Information Set
HHS = Department of Health and Human Services
HQA = Hospital Quality Alliance
JC = Joint Commission
NCS = National Clinical Strategy
NHQR – National Healthcare Quality Report
NHS = National Health Service, United Kingdom
NICE = National Institute for Health and Clinical Excellence, United Kingdom
NQF = National Quality Forum
OASIS = Outcome and Assessment Information Set (CMS)
OBQI = Outcome-Based Quality Improvement
PCPI = Physician Consortium for Performance Improvement (American Medical Association)
PEACE = Palliative Care Quality Measures Project
UNC = University Health Consortium
WHO = World Health Organization

Table

Clarification of terms used in palliative quality of care evaluation

Construct	Definition
Dyspnea	The American Thoracic Society 1999 consensus statement defined dyspnea as “a subjective experience of breathing discomfort that consists of qualitatively distinct sensations that vary in intensity.” ⁹ Dyspnea is multidimensional and can only truly be characterized by patient self-report. The symptom experience involves both the interpreted perception of the sensation of dyspnea and a personal reaction to that sensation.
Palliative Care	World Health Organization (WHO) defines palliative care as “...an approach that improves the quality of life of patients and their families facing the problem associated with life-threatening illness through the prevention and relief of suffering by means of early identification and impeccable assessment and treatment of pain and other problems, physical, psychosocial and spiritual.”
Quality Indicator	A quality indicator is a statement of quality that delineates a recommended care process (what providers do in patient care) or a discrete desired health outcome. It is a general concept supported by existing evidence base that constitute what should occur in clinical care; however it has not been turned into a measure yet that can be systematically used to measure care.
Quality Measure	A quality measure is a fully specified or employed quality metric that is used to assess quality of care. The measure is an operationalized version of a quality process or outcome that at a minimum has defined and detailed numerator and denominator criteria to indicate the intended population, the specifics of recommended care or desired outcome, and exclusions to quality evaluation.
Structural Measure	Structural measures of quality refer to the innate characteristics of a system and its providers, such as the material resources and the organizational and operational aspects of the healthcare delivery system (an example would be the presence or absence of a palliative care consult service in the ICU).
Process Measure	Process measures refer to what health providers do in the delivery of care including assessment of patients, clinical procedures, how humane the care is provided, and adherence to guidelines.
Outcome Measure	Outcome measures evaluate what happens to people, including satisfaction, health-related quality of life, and health status.