

Effective Health Care Program Research Reports

Number 20

Developing Quality Indicators for Cancer End-of-Life Care: Proceedings From a National Symposium

Hsien Seow, Ph.D.

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

Lisa R. Shugarman, Ph.D.

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

Jean S. Kutner, M.D., M.S.P.H.

Karl A. Lorenz, M.D., M.S.H.S.

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

Sydney M. 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: Seow H, Snyder CF, Shugarman LR, et al. Developing quality indicators for cancer end-of-life care: proceedings from a national symposium. *Cancer* 2009 Sep 1;115(17):3820-9.

Suggested citation:

Seow H, Snyder CF, Shugarman LR, Mularski RA, Kutner JS, Lorenz KA, Wu AW, Dy S. Developing quality indicators for cancer end-of-life care: proceedings from a national symposium. Effective Health Care Research Report No. 20. (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

Introduction.....	1
Methods.....	1
Summaries of Domains With More Indicator Development	2
Pain	2
Dyspnea.....	2
Communication, Care Planning, and Decision-Making	3
Psychosocial Issues.....	3
Summaries of Domains With Less Indicator Development	4
Communication Regarding Chemotherapy.....	4
Depression.....	5
Coordination, Continuity, and Care Transitions.....	5
Spirituality and Closure	5
Discussion.....	6
Acknowledgments.....	8
References.....	8
Table	10

Author affiliations:

Hsien Seow, Ph.D.^a

Claire F. Snyder, Ph.D., M.H.S.^a

Lisa R. Shugarman, Ph.D.^b

Richard A. Mularski, M.D., M.S.H.S.^c

Jean S. Kutner, M.D., M.S.P.H.^d

Karl A. Lorenz, M.D., M.S.H.S.^e

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

Sydney M. Dy, M.D., M.Sc.^a

^aJohns Hopkins Bloomberg School of Public Health, Baltimore, MD

^bRAND Corporation, Santa Monica, CA

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

^dUniversity of Colorado School of Medicine, Denver, CO

^eVA Greater Los Angeles Healthcare System, Los Angeles, CA

Abstract

Quality indicators applicable to cancer end-of-life care exist, but have not been widely implemented. To advance this field, we worked with the Agency for Health Care Research and Quality and the National Cancer Institute to organize a national symposium to discuss key issues and future goals, based on a conceptual framework. Discussions focused on eight key domains in end-of-life cancer care: pain, dyspnea, psychosocial care, communication, care planning, depression, spirituality, continuity and coordination, and communication about chemotherapy. Key themes included the need for clarity on definitions and key aspects of care within domains, the need to start implementing indicators in more-developed domains, and the importance of high-quality symptom assessment and documentation of key processes. Key areas for future work include development of more outcome indicators, methods to better incorporate indicators and patient-reported outcomes into clinical processes of care, and coordination across domains and settings. Measuring the quality of end-of-life cancer care is essential to understanding how best to improve patient outcomes and care.

Introduction

There is broad agreement on the need to improve end-of-life care for people with cancer. Improving quality across domains of care requires good measures of quality and outcomes. Measuring and improving the quality of end-of-life cancer care requires indicators that are supported by evidence or expert opinion, accepted as valid by stakeholders, feasible to implement, readily interpretable, and linked to improved outcomes. For some domains, such as pain, there have been numerous indicator development efforts,¹ but many questions remain, including how to meaningfully apply the indicators and improve outcomes. For other domains important to end-of-life care, such as spirituality, a few guidelines have been developed, but there has been little evidence to support their validity or translation into quality indicators.^{2,3} Indicator sets for the quality of cancer care generally address these domains superficially, but few have investigated specific domains in great detail.⁴⁻¹⁵

Multidisciplinary discussions of the state-of-the-science of end-of-life cancer care quality measurement, current barriers, and potential solutions, could advance the development of quality indicators. In-depth discussions based on a conceptual framework and specific domains may help to identify cross-cutting issues and future priorities for the field. We worked with the Agency for Healthcare Research and Quality (AHRQ), the National Cancer Institute (NCI), experts in the field, and other stakeholders to organize a national symposium on these topics. We selected areas that represented a range of issues in cancer end-of-life care, from those with extensive development to those with very few available indicators. Areas with more indicator development included pain, dyspnea, communication/care planning/decision-making, and psychosocial issues. Areas with less indicator development included communication about chemotherapy, depression, coordination/continuity/care transitions, and spirituality/closure. The symposium included experts in oncology, end-of-life care, each domain area, quality indicators and measurement issues, as well as developers of relevant quality indicator sets. Attendees also included representatives from stakeholder groups, such as health maintenance organizations and relevant federal agencies, and providers from different specialties and from the spectrum of settings where cancer care is provided.

Methods

Symposium participants were divided into multidisciplinary groups to address the identified domains. At the symposium, groups identified and refined priority issues to advance quality indicators and potential solutions for their respective domain in breakout sessions. For the domains with more indicator development, groups identified priority issues prior to the symposium via conference calls. We updated reviews on the state-of-the-science for indicators in each domain and provided the reviews to each group.⁴⁻¹⁵ The groups used the conceptual framework for developing end-of-life quality indicators in cancer care as a guide, including the specific indicator evaluation criteria. The indicator evaluation criteria included importance, scientific acceptability, feasibility, and usability.³ Following the breakout sessions, groups presented a summary of their priority issues and solutions to all symposium participants for feedback and comments. Notetakers recorded the discussions of each group. The authors summarized the notes of each group's discussion and presentation after the symposium and solicited further comments from the group moderators and participants by email.

This paper presents the summaries of each domain's priority issues and potential solutions, which are also summarized in Table 1. We conclude by presenting their own analysis of the cross-cutting themes that emerged across the domains and identifying next steps for the field.

Summaries of Domains With More Indicator Development

Pain

Pain is often assessed and documented diligently, but the extent that pain relief and reassessment occurs remains unclear. Quality indicators for pain should not just focus on the level of pain, but also on the extent to which pain has been successfully relieved. Moreover, despite the proliferation of pain assessment tools,¹ quality indicators for pain beyond screening are not widely used, mostly due to lack of evidence. Yet, a sense of urgency exists to issue additional pain indicators without further delay, so that they can begin to benefit patients and improve quality of life. For researchers, this may mean designing indicators and measuring quality simultaneously. Consequently, pain indicator developers should consider moving forward on the “almost ready to endorse” measures identified by the National Quality Forum (NQF).¹⁶ Ultimately, pain relief as an outcome needs to be linked to care processes, to better understand how to achieve quality improvement in this domain.

To overcome the challenges of reporting and documenting pain assessments, pain indicators need to be easily documented and incorporated into workflow processes. Furthermore, pain indicators need to be built into the design of the oncology record or electronic medical record (EMR), whenever possible, to ensure feasible reporting. Development of a measurement toolbox that includes an efficient set of pain indicators would also help standardize measurement and improve reporting.

Dyspnea

Dyspnea, defined as “a subjective experience of breathing discomfort that consists of qualitatively distinct sensations that vary in intensity,”¹⁷ can only be assessed through patient self-report. When observed as a clinical sign, the term “respiratory distress” is used. Whenever possible, dyspnea should be assessed and reported by the patient directly. When patients are unable to self-report, the proxy evaluating the respiratory distress should be reported.

Dyspnea quality indicators are ready for implementation; a variety of measurement tools for eliciting patient-reported symptoms exist that reliably and validly assess dyspnea.¹⁸ No one measurement tool has demonstrated superiority in the palliative care setting. Thus, the group emphasized that the important issue is not which tool to use but that some tool *be* used consistently. At a minimum, dyspnea assessment should include a measure of intensity plus at least one measure of bother, interference, or distress.

Because of the many etiologies of and treatment options for dyspnea, the group did not identify definitive recommendations for how to better link dyspnea quality indicators to improved patient outcomes. However, the group did reach consensus that, at a minimum, some re-assessment should occur and a management plan for addressing dyspnea should be documented.

Communication, Care Planning, and Decision-Making

The group defined the communication, care-planning, and decision-making domain as conversations about care, treatment decisions, needs, and goals of care between the care team, including physicians, and the patient and family. The group primarily discussed communication in the form of verbal conversations or family conferences, but noted that communication could include other forms, such as informational pamphlets.

To be most useful, quality indicators need to measure specific aspects of the communication. Key aspects include a discussion of the prognosis or expected course of the illness, patient priorities and goals of care, practical issues (e.g. housing, meal preparation), higher-level issues (e.g. fears, understanding), and a timeline for reassessment of the goals of care. Indicators should also include clear documentation of the care plan and reassessments of the appropriateness of that plan at later visits. As a first step, initial quality indicators of communication should measure whether or not a relevant conversation occurred. The next step should assess the quality of the conversations. Recommendations included documenting the key elements of the conversations as described above, distributing questionnaires to patients and families to assess their understanding of the conversations, and incorporating questions into the conversation for patients and families that assess their level of understanding. A structural measure could include providing practitioners with training in communication about the goals of care for those with serious chronic illness to increase the likelihood of high quality communication.

Quality indicator developers also face challenges of measuring communication consistently and implementing communication quality indicators. Recommendations to address these challenges include building the documentation of care plans into the patient records to increase the consistency of documentation, and using electronic medical records (EMRs) or other electronic tools to standardize data capture and reporting of key elements of the conversation. Measures need to be simple and easily incorporated into the standard practice of care, such as having checkboxes for physicians to complete on the patient record, with structured ways to revisit the goals of care as the illness progresses.

Psychosocial Issues

The group defined the psychosocial domain as the “psychological and social services and interventions that enable patients, their families, and health care providers to optimize biomedical health care and to manage the psychological/behavioral and social aspects of illness and its consequences,” as adapted from an Institute of Medicine report on this topic.¹⁹ This definition was expanded to include the patient and the family as the unit of care and to address gaps in available family caregiving resources. In particular, this domain should also include caring for the family’s needs specifically, not just helping the family to care for the patient’s needs.

A major issue with current indicator development is that psychosocial care is often ill-defined, making the assessment of the quality of psychosocial care challenging. In terms of defining the elements of quality psychosocial care, the group agreed upon the elements from the Institute of Medicine report, which include: coping with emotions associated with cancer and its treatment; managing the illness; changing behaviors to minimize the impact of the cancer; obtaining resources needed to manage the cancer; managing life disruptions; and managing financial burden. The group included the aspect of grief and bereavement, and, for patients who

are imminently dying, they included crisis management. Moreover, the group accepted the steps in psychosocial care delivery from the report. In order to evaluate whether the psychosocial care not only addressed all these areas but was of good quality, the patient and family perspective would be needed.

An initial approach would be simple indicators that address the following key processes: to identify psychosocial needs, assess for an intervention or referral when needed, and then measure the outcome of intervention; or to perform a basic assessment, define the population with needs, and track referrals. In settings where services should be available (e.g. hospitals), indicators should address whether psychosocial care was administered by appropriately trained professionals, as well as whether care was coordinated with biomedical care, as documented by interdisciplinary team meetings or notation of key psychosocial issues in physician notes.

Summaries of Domains With Less Indicator Development

Communication Regarding Chemotherapy

Use of chemotherapy in patients with end-stage cancer is appropriate in some circumstances, but can also be more harmful than beneficial to patients. High rates of use may indicate poor quality, and indicator benchmarking and tracking rates of chemotherapy use by physicians should be implemented and used for quality improvement. Measures, such as those tracking the percentage of patients receiving chemotherapy in the last two weeks of life,⁶ are already being used with endorsement by the NQF.³ These NQF measures need further development to determine how to apply them, what factors affect performance, and whether they improve patient outcomes.

Structural indicators could address barriers to discussing chemotherapy in end-stage cancer, such as whether and how well physicians have been trained in having these discussions. Indicators should address whether doctors inform patients about whether the treatment they are providing is curative or palliative. Specific indicators could focus on providing patients with information, such as an explicit statement of whether the treatment's intent is to cure the cancer versus relieve symptoms or prolong survival, a more detailed copy or summary of the conversation to the patient and family, or a treatment summary (which would include the prognosis, as well as chemotherapy benefits and risks). Indicators could also address whether there was informed consent for chemotherapy, as in the Quality Oncology Practice Initiative.⁹ Specific aspects of consent could include the benefits and burdens of chemotherapy, which would incorporate a discussion about the expected course of illness and the patient's goals of care.

Ideally, those developing improved indicators in chemotherapy communication would also address the quality of communication. Indicators related to chemotherapy discussions could address whether doctors convey a realistic message and assess the patient's understanding of the conversation. More specifically, indicators regarding informed consent for chemotherapy could measure the extent to which the form was actually explained to the patient or the extent to which the patient understands the content of the consent form. Other indicators about hospice length of stay are also relevant to discussions about chemotherapy, as better integration of palliative care into chemotherapy conversations could allow for earlier hospice referrals. Challenges for future

development include how to apply measures in areas of uncertainty, such as when chemotherapy should be discontinued.

Depression

Key barriers preventing the widespread development and use of quality indicators for depression include the difficulty in linking the processes of screening and diagnosis to outcomes. Moreover, instruments to measure depression are difficult to apply across settings of care and usually require a coordinated and dedicated care team. Often the care team may not have the skills for screening, diagnosis, and treatment, or the resources to follow through. Unfortunately, screening indicators are less meaningful when they are not used in conjunction with indicators about adequate diagnosis and treatment. In addition, clinical decision tools are lacking to help define who would most benefit from treatment.

Short term goals to address the above barriers include starting to implement and consistently use currently recommended quality indicators for depression, such as the ones endorsed by the PEACE project.⁴ An example indicator is, “For patients who screen positive for depression, the percent who receive further assessment, counseling or medication treatment.” Another goal would aim to develop indicators that assess the infrastructure and resources needed for treatment. By comparing performance between settings, using current tools, care teams can improve their current performance and learn best practices from leading institutions. Long term goals include providing incentives to improve performance of consistent depression screening, diagnosis, and treatment.

Coordination, Continuity, and Care Transitions

Sharing information is critical to continuity of care, coordination of care, and care transitions, which applies regardless of whether transitions occur within care settings or across care settings. Examples of tools that identify the key elements of information to transfer include, but are not limited to, SBAR (Situation, Background, Assessment, Recommendation) and “Five-Ps of hand-off,” etc.^{20,21} Indicators assessing whether these aspects of information were shared would serve as an important first step in assessing quality of care for this domain.

While ideally the information shared among the care team would be comprehensive in scope, sharing the patient’s goals of care is paramount. Key aspects of the goals of care are they should be established with the patient and family and reassessed over time based on the patient’s status and treatment options. Indicators should also address the identification of the relevant parties with whom the information should be shared, including relevant providers and appropriate family members. Structural indicators of availability of information technology, including EMRs, are applicable to this domain as they may help facilitate information sharing.

Spirituality and Closure

The domain of spirituality includes the broad concepts of transcendence, relationships, values and beliefs, meaning, purpose, hope, and closure; refining and focusing this definition would be helpful in developing indicators. Research on if, and how, spirituality and spiritual needs are being assessed currently in oncology care would help the process of indicator development. Other research needs include better understanding of what elements of spirituality and closure can and should be measured quantitatively, how to better measure outcomes, and how to include caregivers in the measurement of spirituality.

Short-term recommendations include refining the definition of spirituality as relevant to quality indicators, framing the definition in the overall context of suffering, determining how often spirituality needs to be evaluated and addressed, and developing a survey to capture patient and family perceptions of spiritual care. Setting-specific structural indicators for chaplain availability and staff training are also needed. Longer-term goals include better delineation of spiritual care as part of health care, clearer descriptions of the processes that contribute to quality spiritual care, better survey questions on the processes and outcomes of spiritual care, and structural indicators that include the provision of spirituality curriculum.

Discussion

Examining the priority issues of all the domains exposed a number of cross-cutting themes, which translate across domains with more and less quality indicator development. First, clarity on definitions and key aspects of care is critical to defining the scope and developing high-quality indicators, but often is lacking. For areas with more indicator development, participants felt that there had been sufficient development and consensus that currently endorsed or near-ready indicators should move to widespread use. Indicator use should begin for quality improvement, but not yet for performance measurement, with ongoing rapid evaluation using quality improvement and benchmarking methodologies. Where multiple reasonable measures are available, choosing the best measure is less important than measuring and reporting consistently in a manner that can be standardized and compared across settings.

Simply documenting that key processes are occurring and incorporating this documentation into the flow of clinical care surfaced as a central theme. Documentation of processes should be kept simple. Care teams must assess symptoms as a first step, followed by reassessment. EMRs, worksheets, or templates may aid in consistent and improved documentation and reporting. Some measures require patient-reported outcomes, which should also be documented in the medical record. Making measurement part of the standard of care will require incentives or structures for better assessment and documentation. Toolkits of measures, including a repository of the best tools, will help to standardize care and improve the effectiveness and efficiency of measurement and improvement efforts.

The need for improved communication and coordination pervaded as a fundamental theme across domains. Improving the quality of care requires inquiring about symptoms and discussing issues such as expectations, prognosis, and goals of care. As such, providers need training in the core competencies of communication. The important elements of communication and assessments, such as patient and family understanding, need to be defined, documented, and incorporated into the process of care. Difficulty coordinating across providers and care settings acted as a common barrier to applying quality indicators for all domains.

Indicator efforts need to balance between measuring process and outcomes, such as balancing between documenting that a process has occurred with whether there was high-quality performance. For more advanced domains such as pain, demonstrating relationships between processes and outcomes and documenting outcomes is now needed. For less developed domains, measurement can start with documenting performance of clinical assessments or interventions but should be refined in the future towards the quality of those processes and linkages to improved outcomes.

The symposium's discussions also exposed several important areas of disagreement that require further development. First, although the symposium was based on previous consensus definitions of the population for end-of-life quality indicator development, there was

disagreement about this definition and its application; for example, some participants felt that many domains and quality indicators appropriate for end-of-life care should also apply to the entire spectrum of cancer care. Another area of disagreement involved how to apply indicators to different disciplines and settings, such as whether standards should differ when evaluating resource-rich (comprehensive cancer centers) compared to more limited (community oncology practice) settings. The issue of ideal sources of information was also difficult to resolve, as participants identified strengths and weaknesses of using chart review, patient-reported data, and administrative databases.

Participants did agree on a number of challenges that remain across domains. Key challenges include how best to incorporate measurement needs into electronic medical records, how to ensure that measurement leads to improved outcomes. Applying indicators to different settings, with different structures and resources, can complicate development and comparisons; better understanding of how care for each domain is currently provided or different ways in which care can be implemented would allow for flexible indicator sets. Although the symposium considered the domains separately, there was discussion of the overlap with other domains. Symptoms and other end-of-life issues often interrelate, and may need to be addressed together. Considering domains together, rather than in isolation, could improve efficiency and comprehensiveness as composite outcomes. However, the challenge is to measure care in this way without losing the clarity on individual domains. Reporting challenges also exist across domains, including cognitive impairment, different sources of information, differences across and within settings/providers, and the impact of patient preferences and cultural issues. Patient and family-centered outcomes are a cornerstone of palliative care; indicators need to incorporate direct input from patients and a families in process and outcome measures, both by specific domain and overall.

The recommendations summarized here are relevant to a variety of stakeholder organizations, many of which had representatives attend the meeting, and include government agencies (National Cancer Institute, Veterans' Administration), quality organizations (National Quality Forum), health care organizations, and researchers, developers, and policymakers interested in measuring and improving quality for end-of-life cancer care. The key policy recommendation was that indicators in well-developed areas, such as pain, are ready for implementation; other recommendations will be useful to ongoing and planned efforts to further end-of-life indicator development and include these elements in broader cancer quality initiatives. Implementing these recommendations will require ongoing efforts, increased involvement, and greater collaborations between health care professionals, organizations, and decision-makers, including the invitees. The symposium served as one step in the process of developing and improving quality indicators and its recommendations should be considered along with other related projects aimed at improving quality of cancer end-of-life care. Plans are ongoing to continue the discussions at the symposium and use them as a basis for quality measurement projects.

In summary, indicators for end-of-life care differentiate themselves from other cancer care indicators in a variety of ways. End-of-life indicators may be supported less by high quality research evidence, (e.g. large clinical trials), and more by expert consensus and demonstrations that their use improves outcomes. Patient-reported outcomes are necessary to measure care, and administrative data or medical records are insufficient in their current forms for all but a few screening indicators. Better documentation of communication and coordination are needed to improve care. Although developing measures for improving end-of-life care remains

challenging, the urgency to do so intensifies as patient outcomes at the end-of-life continue at suboptimal levels despite improvement efforts. Only through developing better quality indicators and improving their use can we measure where providers most need to improve and accurately document the impact of our interventions.

Acknowledgments

The Symposium on Developing a Framework to Assess Cancer Quality Indicators for End-of-Life Care was held in Baltimore, MD, on April 28, 2008. We gratefully acknowledge the support of Eric Bass, MD, MPH, Christine Weston, PhD, MEd, Kristina Weeks, BA, BS, Jonathan P. Weiner, PhD, and Joyce Hines, as well as all the attendees at the symposium: Terry Altilio, LCSW, Robert Arnold, MD, Colleen Apostol, RN, OCN, CHPN, Steven Asch, MD, MPH, Ethan Basch, MD, MSc, Ann Berger, MSN, MD, Sepheen C. Byron, MHS, Margaret L. Campbell, PhD, RN, FAAN, Michael Carducci, MD, Steven Clauser, PhD, Stephen R. Connor, PhD, Joanne Cuny, RN, MBA, Molla S. Donaldson, DrPH, MS, Deborah Dudgeon, MD, Craig Earle, MD, Betty R. Ferrell, PhD, FAAN, John Fetting, MD, Esme Finlay, MD, Michael J. Fisch, MD, Marian Grant, CRNP, Eva Grunfeld, MD, DPhil, FCFP, Paul Han, MD, MA, MPH, Catherine D. Harvey, DrPH, J. Russell Hoverman, MD, PhD, Nancy Hutton, MD, Javier R. Kane, MD, Robert D. Kerns, PhD, Rashmi Kumar, MD, Elizabeth Lamont, MD, William Lawrence, MD, Mark Leenay, MD, Joanne Lynn, MD, Jennifer Malin, MD, PhD, Terri L. Maxwell, PhD, APRN, BC-PCM, Kristen McNiff, MPH, Melanie Merriman, PhD, MBA, R. Sean Morrison, MD, Judith E. Nelson, MD, JD, Leslie Piet, RN, MA, CCM, Aisha T. Pittman, MPH, Lori A. Pollack, MD, MPH, Arnold L. Potosky, PhD, Holly G. Prigerson, PhD, Christina M. Puchalski, MD, FACP, Bryce B. Reeve, PhD, Thomas J. Smith, MD, Carol Spence, PhD, Diane St. Germain, RN, MS, CRNP, Joan Teno, MD, MS, Howard Tuch, MD, MS, Anne Walling, MD, and Cynthia Williams, DO.

References

1. Holen JC, Hjermstad MJ, Loge JH, et al. Pain assessment tools: is the content appropriate for use in palliative care? *J Pain Symptom Manage* 2006;32(6):567-580.
2. National Consensus Project for Quality Palliative Care. Clinical practice guidelines for quality palliative care. 2004: Pittsburgh, PA.
3. National Quality Forum. A national framework and preferred practices for palliative and hospice care quality. 2006: Washington, DC.
4. Carolinas Center for Medical Excellence. Palliative care quality measurement project. Medicare quality improvement community (MedQIC - Hospice). Available at: <http://www.medqic.org>. Accessed: 2008.
5. Connor SR, Teno J, Spence C, et al. Family evaluation of hospice care: results from voluntary submission of data via website. *J Pain Symptom Manage* 2005;30(1):9-17.
6. Earle CC, Neville BA, Landrum MB, et al. Evaluating claims-based indicators of the intensity of end-of-life cancer care. *Int J Qual Health Care* 2005;17(6):505-509.
7. Etzioni S, Chodosh J, Ferrell BA, et al. Quality indicators for pain management in vulnerable elders. *J Am Geriatr Soc* 2007;55(Suppl 2):S403-S408.
8. Grunfeld E, Lethbridge L, Dewar R, et al. Towards using administrative databases to measure population-based indicators of quality of end-of-life care: testing the methodology. *Palliat Med* 2006;20(8):769-777.

Effective Health Care Research Report Number 20

9. Jacobson JO, Neuss MN, McNiff KK, et al. Improvement in oncology practice performance through voluntary participation in the Quality Oncology Practice Initiative. *J Clin Oncol* 2008;26(11):1893-1898.
10. Lorenz KA, Lynn J, Dy SM, et al. Quality measures for symptoms and advance care planning in cancer: a systematic review. *J Clin Oncol* 2006;24(30):4933-4938.
11. Lorenz KA, 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.
12. Miyashita M, Morita T, Tsuneto S, et al. The Japan Hospice and Palliative Care Evaluation Study (J-HOPE Study): Study Design and Characteristics of Participating Institutions. *Am J Hosp Palliat Care* 2008;25(3):223-232.
13. Mularski RA, Dy SM, Shugarman LR, et al. A systematic review of measures of end-of-life care and its outcomes. *Health Serv Res* 2007;42(5):1848-1870.
14. Nelson JE, Mulkerin CM, Adams LL, et al. Improving comfort and communication in the ICU: a practical new tool for palliative care performance measurement and feedback. *Qual Saf Health Care* 2006;15(4):264-271.
15. Twaddle ML, Maxwell TL, Cassel JB, et al. Palliative care benchmarks from academic medical centers. *J Palliat Med* 2007;10(1):86-98.
16. National Quality Forum. Quality of cancer care measures' project symptom management/end-of-life cancer technical panel. 2006.
17. American Thoracic Society. Dyspnea. Mechanisms, assessment, and management: a consensus statement. *Am J Respir Crit Care Med* 1999;159(1):321-340.
18. 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(3):177-191.
19. Institute of Medicine. Cancer care for the whole patient: Meeting psychosocial health needs. Available at <http://www.iom.edu>. Accessed 2008.
20. Haig KM, Sutton S, Whittington J. SBAR: a shared mental model for improving communication between clinicians. *Jt Comm J Qual Patient Saf* 2006;32(3):167-175.
21. Sandlin D. Improving patient safety by implementing a standardized and consistent approach to hand-off communication. *J Perianesth Nurs* 2007;22(4):289-292.

Table 1. Priority Issues and Potential Solutions for Domains

Domains	Priority Issues	Potential Solutions
Pain	Better link pain indicators to improved patient outcomes	<ul style="list-style-type: none"> • Emphasize the importance of pain relief, not just pain intensity.
	Distinguish the use of pain indicators in quality improvement versus performance measurement	<ul style="list-style-type: none"> • Focus the use of indicators for quality improvement; • Understand clinical triggers in the process of care
	Overcome documentation and reporting challenges	<ul style="list-style-type: none"> • Provide incentives for documentation and reassessment; • Interface with the development of patient reported measures and link with oncology health records; • Develop an efficient indicator set via a measurement toolbox; • Consider assessing pain in the context of assessing other domains, such as quality of life, spirituality, and psychosocial issues
Dyspnea	Develop a consensus definition for the clinical assessment of dyspnea	<ul style="list-style-type: none"> • Clinical assessment of dyspnea should include at least one measure of intensity and at least one measure of bother, interference, or distress
	Implement dyspnea quality indicators that focus on patient outcomes	<ul style="list-style-type: none"> • Further work in this area is needed; • Assessment and re-assessment are recommended, ideally with some documentation of a management plan
	Identify data sources for dyspnea measurement	<ul style="list-style-type: none"> • Patients are the preferred source of dyspnea reports; • When the patient is unable to self-report, proxy reports and behavioral assessments of respiratory distress may be required
Communication, care planning, and decision-making	Define the aspects of communication to measure that will improve patient outcomes	<ul style="list-style-type: none"> • Begin by simply documenting whether the conversation occurred and then measuring the rate of occurrence; • Standardize the key elements of care planning communication
	Determine how to measure the quality of communication	<ul style="list-style-type: none"> • Assess patient understanding; • Determine key elements of the discussions about goals of care and then measure the rate of occurrence of the elements; • Evaluate whether providers have had care planning communication training
	Consistently measure communication	<ul style="list-style-type: none"> • Incorporate communication documentation as a field in the patient record; • Provide incentives for documentation of these conversations; • Standardize data reporting of care planning and goals of care; • Have informed consent for chemotherapy (i.e. the benefits and burdens) and include a discussion about goals of care during the consent process
Psychosocial issues	Define aspects of psychosocial care to allow for better specified indicators	<ul style="list-style-type: none"> • Use adapted Institute of Medicine definition as the standard; • Include the family in the unit of care
	Accurately assess whether care teams provide quality psychosocial care	<ul style="list-style-type: none"> • Assess training of providers; • Standardized psychosocial screening across providers; • Coordination across settings

Effective Health Care Research Report Number 20

Domains	Priority Issues	Potential Solutions
	Identify the type of data to be collected	<ul style="list-style-type: none"> • Better documentation, including assessment, referral, followup, and coordination in patient record; • The person documenting will depend on setting, and should be recorded by a skilled provider (e.g. social worker, trained nurse) when available; • Document during interdisciplinary team meetings, and physicians should note key psychosocial issues in the biomedical context;
Communication about chemotherapy	Implement benchmarking of chemotherapy indicators and tracking rates of use by physicians for quality improvement	<ul style="list-style-type: none"> • Begin using indicators about overuse of chemotherapy at the end-of-life and hospice referral length of stay, and consistently report and compare rates
	Better standardize discussions about chemotherapy intent and develop associated quality indicators	<ul style="list-style-type: none"> • Use available worksheets or templates that help guide discussions about treatment intent; • Implement structural indicators on whether physicians are trained in discussing chemotherapy in end-stage cancer; • Implement indicators that measure whether doctors inform patients that the treatment they are providing is curative or palliative
	Identify the quality of communication	<ul style="list-style-type: none"> • Develop treatment consent indicators that measure patients' understanding of conversation
Depression	Better link screening and diagnosis depression indicators to improved patient outcomes	<ul style="list-style-type: none"> • Begin by consistently implementing screening indicators; • Compare practice performance between settings for quality improvement
	Overcome inadequate resources, training, and skills to treat depression	<ul style="list-style-type: none"> • Develop improved clinical decision tools to determine who would benefit most from treatment; • Provide incentives to improve performance in depression indicators; • Conduct resource assessment for treatment needs
Continuity, coordination, and care transitions	Define what key information needs to be shared to ensure continuity of care that will improve patient outcomes	<ul style="list-style-type: none"> • Use existing tools that identify key aspects of care process and information to transfer; • Implement indicators that measure whether these aspects of information were shared; • Document goals of care more consistently
	Identify key players to share information between and feasible methods to do so	<ul style="list-style-type: none"> • Identify relevant providers, care team members, and appropriate family members; • Structural indicators of information technology, including EMRs, can facilitate information sharing.
Spirituality and closure	Define key elements of spirituality as relevant to quality indicators	<ul style="list-style-type: none"> • Define clearly what processes contribute to quality spiritual care; • Develop a survey for patient and family perceptions of spiritual care and eventually patient and/or family-reported outcome measures for spirituality; • Conduct further research on what elements of spirituality and closure can and should be measured quantitatively
	Include spiritual history/assessment in care	<ul style="list-style-type: none"> • Train staff to conduct spiritual assessments or appropriate referral mechanisms; • Implement setting-specific structural indicators for chaplain availability, appropriate staff training, and spirituality curriculum