Measuring What Matters: Top-Ranked Quality Indicators for Hospice and Palliative Care From the American Academy of Hospice and Palliative Medicine and Hospice and Palliative Nurses Association

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Abstract

Context. Measuring quality of hospice and palliative care is critical for evaluating and improving care, but no standard U.S. quality indicator set exists.

Objectives. The Measuring What Matters (MWM) project aimed to recommend a concise portfolio of valid, clinically relevant, cross-cutting indicators for internal measurement of hospice and palliative care.

Methods. The MWM process was a sequential consensus project of the American Academy of Hospice and Palliative Medicine (AAHPM) and Hospice and Palliative Nurses Association (HPNA). We identified candidate indicators mapped to National Consensus Project (NCP) Palliative Care Guidelines domains. We narrowed the list through a modified Delphi rating process by a Technical Advisory Panel and Clinical User Panel and ratings from AAHPM and HPNA membership and key organizations.

Results. We narrowed the initial 75 indicators to a final list of 10. These include one in the NCP domain Structure and Process (Comprehensive Assessment), three in Physical Aspects (Screening for Physical Symptoms, Pain Treatment, and Dyspnea Screening and Management), one in Psychological and Psychiatric Aspects (Discussion of Emotional or Psychological Needs), one in Spiritual and Existential Aspects (Discussion of Spiritual/Religious Concerns), and three in Ethical and Legal Aspects (Documentation of Surrogate, Treatment Preferences, and Care Consistency with Documented Care Preferences). The list also recommends a global indicator of patient/family perceptions of care, but does not endorse a specific survey instrument.

Conclusion. This consensus set of hospice and palliative care quality indicators is a foundation for standard, valid internal quality measurement for U.S. settings. Further development will assemble implementation tools for quality measurement and benchmarking. J Pain Symptom Manage 2015;49:773–781. © 2015 American Academy of Hospice and Palliative Medicine. Published by Elsevier Inc. All rights reserved.

Key Words

Palliative care, pain measurement, hospice care, quality of health care, quality indicators, advance care planning, patient satisfaction

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Introduction

Far too many patients and families in the U.S. experience unnecessary physical and emotional suffering during serious and life-threatening illnesses. Recent studies have demonstrated gaps in quality of care in domains such as pain and symptom management, communication, and care planning across settings such as hospitals, nursing homes, and ambulatory care. Palliative care is defined as care that provides relief from symptoms and supports quality of life for patients with serious advanced illness and their families, and hospice care is an approach focused on patients with limited life expectancy and their families. Accumulating research demonstrates that interventions such as ambulatory palliative care clinics, structured goals of care discussions in critical care, and outpatient nurse-led interventions targeting patient/family pain management can improve outcomes such as patient and family satisfaction and health care utilization.

Measuring the quality of care delivery is integral to hospice and palliative care programs, as specified by the National Consensus Project (NCP) Clinical Practice Guidelines and the Joint Commission Advanced Certification Program for Palliative Care and the Centers for Medicare & Medicaid Services (CMS) for the hospice programs. A critical first step in improving care is demonstrating where quality deficits exist compared with national benchmarks and determining where quality improvement initiatives are most needed and most likely to be beneficial, but no national U.S. (or universal) standards for measurement or databases that would support benchmarking yet exist. Quality indicator sets for a variety of relevant populations and settings have been developed and tested and the National Quality Forum (NQF) has endorsed a group of palliative care indicators suitable for accountability, such as public reporting. However, many of the indicators intended for accountability may not be the most appropriate for internal use in clinical programs, and a standard, concise, cross-cutting set of indicators that can be used internally for benchmarking, comparison across programs, and quality improvement is needed. Many palliative care programs are not yet routinely measuring quality, many are using locally developed, non-validated indicators, and for those who wish to measure quality, there are no nationally used sets with benchmarking that apply across populations and settings.

The Quality and Practice Standards Committee of the American Academy of Hospice and Palliative Medicine (AAHPM), therefore, initiated the Measuring What Matters (MWM) consensus project, which was joined by the Hospice and Palliative Nurses Association (HPNA) Research Advisory Council. The overall goal of the project was to recommend a concise portfolio of valid, clinically relevant, cross-cutting performance indicators for internal measurement for hospice and palliative care programs. The intent was to develop a common core set from which programs could select, to help create standards for quality measurement of palliative care in the U.S. and allow for national benchmarking. The aspirational goal was an initial set of process and outcome indicators that apply regardless of diagnosis, organizational structure, or setting, although the MWM team recognized that such indicators may not always be appropriate or not yet exist and that some included indicators as currently defined may not apply across populations and settings. The MWM team acknowledged that promoting high-quality hospice and palliative care indicators for accountability with CMS and other groups is also an important goal, but may be less relevant for program development or for improving the patient and family experience of care; this was, therefore, not a goal of the MWM project. In this article, we describe the MWM methodology and the initial core consensus set of quality indicators.

Methods

MWM was a sequential consensus project, directed by a partnership between AAHPM and HPNA with a modified Delphi rating process by first a Technical Advisory Panel (TAP) and then a Clinical User Panel (CUP), followed by input solicited from AAHPM and HPNA membership and from external organizations and patient advocacy groups to obtain the final indicator set (Table 1). The project goals described above guided the MWM process. In particular, the MWM team aligned the set with the NCP guidelines, including organizing by the eight domains, and other existing quality initiatives whenever possible. The team envisioned the indicator set for population-level measurement, and it may be insufficient for measurement targeting specific settings or populations. The MWM process also evaluated whether denominators of existing indicators should be considered for future modification to be more inclusive and cross-cutting across settings or populations.

Identifying Indicators

The MWM project began by identifying existing U.S. process and outcome indicators relevant to hospice and palliative care, available in the public domain as of October 2013 and specified for U.S. data sources and developed through a rigorous process and/or tested for reliability and validity in English. Sources included indicators endorsed by the NQF and/or in
The MWM team identified existing indicators
- Relevant to U.S. hospice and palliative care,
- Available in the public domain as of October 2013, and
c. Developed through a rigorous process and/or tested for reliability and validity.
2. The Technical Advisory Panel (TAP) rated indicators on their scientific soundness and referred a set of indicators (n = 34) for review by the Clinical User Panel (CUP).
3. The CUP rated those indicators based on three dimensions:
   a. How meaningful is this for patients/families?
   b. How actionable is this for providers/organizations?
   c. How large is the potential impact?
4. The CUP achieved consensus on the top 12 indicators for further input.
5. The draft set of 12 indicators was posted on the American Academy of Hospice and Palliative Medicine (AAHPM)’s web site to elicit feedback from AAHPM and Hospice and Palliative Nurses Association (HPNA) members and their interdisciplinary teams, and asked them to reduce the list of 12 measures down to 10 (or less) of the best measures.
6. The draft set of 12 indicators was distributed to key relevant external organizations and patient advocacy groups for a final set of ratings.
7. The MWM team compiled the input from the membership, teams, organizations, and advocacy groups for the final consensus set of 10 indicators.

Table 1
Steps in the Measuring What Matters (MWM) Process for Selecting the Initial Consensus Set of Quality Indicators

<table>
<thead>
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the Agency for Healthcare Research and Quality (AHRQ) Quality Measures database, as well as indicators included in the PEACE Palliative Care and Hospice, Cancer Quality-ASSIST supportive oncology, American Society for Clinical Oncology (ASCO) Quality Oncology Practice Initiative (QOPI®) Care at the End of Life, and Assessing Care of Vulnerable Elders (ACOVE) Palliative Care and End of Life sets, indicators developed by the National Hospice and Palliative Care Organization (NHPCO) and American Medical Association—convened Physician Consortium for Performance Improvement (PCPI), and indicators used by the CMS. Indicators were considered relevant to hospice and palliative care based on the numerator. If the numerator or topic of the indicator was related to the NCP domains or preferred practices of palliative care, the indicator was considered for inclusion. Members of the project steering committee then reviewed the compiled list and identified any missing indicators. From these sources, the MWM team identified 75 existing indicators that met criteria, and classified them by NCP domain and compiled existing specifications and evidence about each indicator. Almost all indicators had reliability and validity testing in palliative care populations.

Panel Ratings and Public Comment
Technical Advisory Panel. The key purpose of the TAP was to judge the technical strength of existing indicators. The MWM team recruited 11 key researchers on quality measurement in hospice and palliative medicine for the TAP and co-chairs from AAHPM and HPNA. After an introductory instructional webinar, all members of the TAP were given detailed information on the indicators and associated evidence, including their reliability and validity testing, and asked to review and rate the indicators on a scale from one to nine, where one indicated low and nine high scientific soundness (Appendix). When rating each indicator, in addition to using the specifications and evidence provided about each indicator, the TAP members considered the AHRQ desirable attributes of quality indicators:

- Importance
- Scientific soundness: clinical logic
- Scientific soundness: indicator properties, including evidence for reliability and validity
- Feasibility

The TAP members rated each indicator twice: once for the indicator as specified and once for the indicator concept (the numerator only), and also could provide free-text comments. The purpose of the indicator concept rating was to determine if the numerator was a good candidate for future indicator development using a global all-palliative care population denominator to be developed in the future.

The TAP members then participated in a conference call to discuss the indicators, focusing particularly on those with disagreement, defined as at least one rating lower than four or at least three ratings lower than seven. Members could discuss issues raised and advocate for or against indicators. The TAP members then rated the indicators a second time using the same process as the first round. This process identified 34 indicators sufficiently highly rated for scientific soundness to advance to the CUP rating process.

Clinical User Panel. The purpose of the CUP process was to select the indicators that were the most clinically important and usable. The goal was to form a concise measurement set of approximately 10 indicators, although it was recognized that the final number of indicators would be responsive to the concerns of both comprehensiveness and brevity. The MWM team recruited co-chairs from AAHPM and HPNA and 27 members for the CUP to represent diversity in settings where hospice and palliative services are provided; patient populations and illnesses; and providers including physicians, nurses, social workers, chaplains, and grief counselors, as well as consumer groups and quality organizations. The CUP reviewed the 34 indicators forwarded by the TAP using a similar process as the TAP. The CUP rated the indicators on meaningfulness for patients and families, actionability for providers and organizations (including both
feasibility of measurement and possibility of making changes based on results), and potential impact (prevalence of problem and/or amount of possible improvement; Appendix). After the survey and discussion webinar and further consolidation/prioritization from the CUP co-chairs considering all feedback and comments, consensus was reached on 12 cross-cutting indicators from a variety of sources to submit for the last steps in the process.

In the final steps, the MWM team distributed information on the project and on the 12 indicators to the AAHPM and HPNA membership and their teams and to key relevant stakeholders for further ratings and comment on which indicators were highest priority and which should not be included, before winnowing down to a final list of 10 indicators. In total, feedback was received from 264 individuals, including 131 physicians, 106 nurses, 10 social workers, four pharmacists and three chaplains, and 27 organizations, including the American Academy of Neurology, American Academy of Pain Medicine, American Academy of Pediatrics, American College of Emergency Physicians, American Academy of Neurology, American Academy of Pediatrics, American College of Emergency Physicians, American Geriatrics Society, Association of Professional Chaplains, Center to Advance Palliative Care, NHPCO, National Palliative Care Research Center, Oncology Nursing Society, Social Work Hospice & Palliative Network, and The Joint Commission.

Results

Description of Selected Indicators

The final MWM quality indicator set includes 10 indicators (Table 2). These include one in the NCP domain of Structure and Process of Care (Comprehensive Assessment), three in the domain of Physical Aspects of Care (Screening for Physical Symptoms, Pain Treatment, and Dyspnea Screening and Management), one in Psychological and Psychiatric Aspects of Care (Discussion of Emotional or Psychological Needs), one in Spiritual and Existential Aspects of Care (Discussion of Spiritual/Religious Concerns), and three in Ethical and Legal Aspects of Care (Documentation of Surrogate, Treatment Preferences, and Care Consistency with Documented Care Preferences). In addition, the MWM list recommends that a global indicator of care from the patient/family perspective be included, but the MWM process did not endorse a specific measure. Measures of the patient/caregiver experience that were considered and not endorsed by the NQF (Discussion of Spiritual/Religious Concerns and Treatment Preferences) are described in Table 3. No indicators were included in the domains of Social Aspects of Care, Cultural Aspects of Care, and Care at the End of Life, highlighting gaps in areas where indicators may not be supported by current evidence or may potentially not be appropriate for evaluating care.

None of the MWM indicators are disease-specific and almost all apply to any patients receiving palliative or hospice care services, although one is for vulnerable elders (people older than 65 years at increased risk for death or functional disability). Most are from the PEACE data set and apply to hospitalized or hospice patients; one (Discussion of Spiritual/Religious Concerns) is for hospice only and one (Dyspnea Screening and Treatment) is for ambulatory care (by physicians). Most address processes of care. All indicators would require medical record review or duplicate data entry into a quality database, except for patient/family perceptions of care. Only two are currently endorsed by the NQF (Discussion of Spiritual/Religious Concerns and Treatment Preferences).

Discussion

In summary, the MWM project, led by the AAHPM and HPNA with input from a wide variety of stakeholder and patient advocacy groups, assembled a consensus-based concise set of process and outcome quality indicators for internal current use for quality measurement and improvement in settings caring for hospice and palliative care patients. These indicators cover five of the eight domains of the NCP Palliative Care Guidelines and most are applicable to broad hospice and palliative care populations and more than one setting (hospital and hospice care); only one is for the ambulatory setting. Most are process indicators and require medical record abstraction or separate data entry. The MWM list also includes a global indicator for patient/family experience of care, although no consensus developed for a specific measurement tool (the measure for hospices, the Family Evaluation of Hospice Care, was being replaced at the time of this project by the Consumer Assessment of Healthcare Providers and Systems hospice survey) and the group recommended that additional measure development was needed.

Some of these indicators have been used and tested more widely than others, and further refinement and evaluation are needed. Many supporting tools already exist for the PEACE indicators,12 and further development of accompanying tools for the indicator set, including details on standardizing data abstraction, measurement specifications, benchmarking, and evidence-based quality improvement, as well as potential recommendations for modifications of the indicators based on experience with them, is needed. The MWM panel recognized that quality indicators are needed both to evaluate the quality of hospice and palliative care programs and to evaluate the quality
of palliative care provided more broadly within settings by all providers to patients with palliative care needs, and further testing should evaluate both of these applications. Because the purpose of the project was to define cross-cutting indicators, initiatives targeting quality measurement in specific populations (e.g.,
or settings (e.g., nursing homes) may benefit from using more targeted indicators. In addition, the purpose of the MWM project was not to identify or test indicators for public reporting, which requires a different evaluation process; the NQF, which evaluates indicators for public reporting, has endorsed a number of indicators relevant to palliative and hospice care (only two of the MWM set are endorsed by the NQF). Finally, the MWM team emphasizes that quality measurement is only one small component of ensuring the best hospice and palliative care; attention to structure, program development, evidence-based practice, education, and quality improvement are all also key to improving care for patients and families.

The MWM list includes cross-cutting indicators in five of the eight NCP domains, leaving social aspects of care, cultural aspects of care, and care of the imminently dying without any defined indicators in this set. Although a number of indicators in these domains were considered by the expert panels, the lack of included indicators in these domains in the final MWM set reflects the lack of scientific evidence and insufficient documentation in the medical record for feasible abstraction. In addition, some of these aspects, such as cultural aspects of care, are less practical for process and outcome quality measurement, which requires issues that can be objectively measured in standard ways that reflect quality across populations. Potentially, structural indicators, such as the availability or penetration of chaplaincy services, may be more appropriate for these domains. Some of the domains, such as physical and ethical and legal aspects of care (which have the most indicators), are more likely to be documented and easier to objectively measure than others, such as social aspects of care. For example, whether or not a patient has life-sustaining treatment preferences documented in the chart is easier to objectively measure than whether or not the provider developed a comprehensive social care plan, addressing issues such as relationships and caregiver stress, as recommended by the NCP guidelines.

The lack of included indicators in the domain of care of the imminently dying is a clear gap critical to hospice and palliative care, where more objective markers exist but further development is needed. Eight of the nine indicators considered in this domain were outcome measures of health care utilization (the ninth was family evaluation of bereavement services; the global indicators discussed previously also address this domain from the patient/caregiver perspective). In particular, two NQF-endorsed Quality Oncology Practice Initiative indicators for cancer patients,

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whether or not a patient received hospice for less than three days and proportion with more than one emergency room visit in the last 30 days of life, were considered throughout the MWM process. However, many concerns about these two Quality Oncology Practice Initiative indicators were raised by the panels, membership, and stakeholder groups. These measures were tested using Medicare claims data and have been benchmarked only for cancer patients; and they require knowing about patients’ outcomes outside a health system and who were within the last 30 days of life, which is generally challenging data to obtain for palliative care providers not in hospice settings. Outcome indicators also are generally risk-adjusted and have exclusions, which have not yet been developed for these indicators and could significantly affect outcomes. They also could be very dependent on local structure, such as availability of urgent care and the efficiency of hospice admission processes. Finally, these indicators may not accurately reflect patient and family perceptions of quality of care, especially across cultures, as studies have found that most caregivers feel that the length of stay in hospice was sufficient and that caregivers in Japan did not rank emergency department use highly as an indicator of quality of care.

Ideal indicators for care at the end of life could include patient and family preferences for hospice care and the timing of initial hospice referral and admission accounting for whether any lag between referral and admission was patient preference or a system performance issue. On the other hand, outcomes such as hospice length of stay can be integrative and identify potential issues within a setting that need to be addressed (e.g., very low hospice stays could indicate that information is not being provided early enough, referral processes are too slow, or coordination with hospices is poor). However, these would need further detailed evaluation to identify the source of the issue before attempts to improve quality can be made.

The MWM process and the indicator set have a number of limitations. The MWM set is based on an extensive process of expert consensus and diverse input, but will require ongoing efforts to further evaluate feasibility for routine data collection, usability for quality improvement projects, links between process and outcome indicators, and updates as new and revised indicators become available. Using indicators from the set will require careful monitoring for unintended negative consequences, such as focusing initiatives only on such areas where indicators are robust and neglecting important areas where performance may be more difficult to measure. Not all indicators may apply to all settings or populations, and programs will need to select those that are most appropriate to their internal population, needs, and opportunities for improvement. Further research with benchmarking and evaluation of the impact of contextual factors, such as electronic health record system, academic status, or quality program structure, are needed to improve the usability of the indicators. None of the indicators have been evaluated in pediatrics, and evaluation specific to geriatric populations is limited.

Patient/caregiver evaluations of care are critical to hospice and palliative care, as medical record review process indicators address only a small fraction of care and cannot measure many important issues—including the quality of communication, coordination, respect, and attention to patient preferences. However, there is no universally agreed-on measure in palliative care; different measures have been developed and are used in different settings, and no current indicators we identified that met eligibility criteria crossed settings. The consensus and stakeholder input processes, therefore, did not endorse any specific measure, and further measure development is needed, but some process for assessing relevant patient/caregiver input should be included in settings providing care to palliative or hospice patients.

Conclusion

In conclusion, the MWM Project of the AAHPM and HPNA has assembled a list of 10 consensus indicators for internal measurement of quality in settings serving hospice and palliative patients. Although this set serves as an initial starting place for standardizing U.S. measurement and benchmarks for care, more development and partnerships with organizations to develop benchmarking is needed, and additional or revised indicators may be needed for particular settings or populations. Further research is needed to evaluate how best to define palliative care populations of interest for quality measurement, and how to measure the quality of hospice and palliative care both overall in different settings and for patients served by hospice and palliative care services. Finally, as evaluation of this national U.S. indicator set occurs, consideration of including structural and newly developed indicators and coordination with lessons learned from individual hospice and palliative care programs in the U.S., relevant quality programs such as the ASCO QOPI and other emerging international palliative care quality measurement projects, such as those in Australia, Belgium, and The Netherlands, will help to maximize the value of quality measurement in the U.S.
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References


Appendix

Example Questions From the TAP and CUP Surveys