

Special Article

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.¹ 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.^{2–4} 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.¹ 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.⁵

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 Care⁶ and the Centers for Medicare & Medicaid Services (CMS) for the hospice programs.⁷ 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^{8–11} and the National Quality Forum (NQF) has endorsed a group of palliative care indicators¹¹ 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,¹ 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

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