Review Article

Quality Indicators for Palliative Care: Update of a Systematic Review

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Abstract

Context. In 2007, a systematic review revealed a number of quality indicators referring mostly to palliative care outcomes and processes. Psychosocial and spiritual aspects were scarcely represented. Most publications lacked a detailed description of the development process. With many initiatives and further developments expected, an update is needed.

Objectives. This update gives an overview of the published quality indicators for palliative care and identifies any new developments since 2007 regarding the number and type of indicators developed and the methodology applied.

Methods. The same literature search as in the 2007 review was used to identify relevant publications up to October 2011. Publications describing development processes or characteristics of quality indicators for palliative care were selected by two reviewers independently.

Results. The literature search resulted in 435 hits in addition to the 650 hits found in the previous review. Thirteen new publications were selected in addition to the 16 publications selected earlier, describing 17 sets of quality indicators containing 326 indicators. These cover all domains of palliative care as defined by the U.S. National Consensus Project. Most indicators refer to care processes or outcomes. The extent to which methodological characteristics are described varies widely.

Conclusion. Recent developments in measuring quality of palliative care using quality indicators are mainly quantitative in nature, with a substantial number of new indicators being found. However, the quality of the development process varies considerably between sets. More consistent and detailed methodological descriptions are needed for the further development of these indicators and improved quality measurement of palliative care. J Pain Symptom Manage 2013;46:556–572. © 2013 U.S. Cancer Pain Relief Committee. Published by Elsevier Inc. All rights reserved.

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Accepted for publication: September 19, 2012.

Key Words

Palliative care, quality of care, quality indicators

Introduction

Quality indicators can play an important role in offering insight into the quality of care provided and subsequently enabling improvements to care where needed. Quality indicators are explicitly defined measurable items referring to the outcomes, processes, or structure of care. They are usually described with a numerator, denominator, and/or performance standard. Quality indicators can indicate either problems or good quality in relevant care domains.

In palliative care today, there is an increasing interest in the quality of care and, more specifically, in quality indicators. In 2005, the National Consensus Project for Quality Palliative Care (NCP) in the U.S. published an overview of eight domains⁴ covering the World Health Organization's well-known definition of palliative care.⁵ Clinical guidelines were subsequently developed for each of these NCP domains in 2006 and were updated in 2009. These guidelines defined preferred practice for each domain, in an effort to guide improvement in the quality of palliative care. The NCP stated that the next step after developing these guidelines had to be the development, testing, and implementation of quality indicators, to enable the determination, comparison, and continual improvement of the quality of care. 4,6,7 In addition, in 2009, the Council of Europe stated that "the definition and adoption of indicators of good palliative care assessing all dimensions of care from the perspective of the patient should be encouraged."8

Furthermore, in 2009, Pasman et al. published a systematic international literature review (performed in 2007) on quality indicators for palliative care. This review revealed that a number of quality indicators for palliative care had already been developed, particularly in the U.S. However, the existing quality indicators showed some limitations. First, most quality indicators concerned the processes and outcomes of palliative care, whereas there were few indicators dealing with the organizational structure of palliative care. Moreover, not all domains of palliative care were covered to the same degree:

there was an underrepresentation of psychosocial, spiritual, and cultural domains. Finally, most indicators were restricted to one setting or patient group. The authors expressed the need for the further development of quality indicators, with detailed methodological specifications, that enable accurate assessment and monitoring of the quality of palliative care.

In general, systematic reviews synthesize the existing research findings. 10 Systematic reviews need to be kept up to date, 11 particularly when there are indications that new relevant research has become available, to prevent the reviews from becoming out of date and their results becoming incomplete. The Cochrane Handbook recommends that authors should assess frequently whether relevant research is being published, so they are able to judge whether and when the review needs updating. 12 There has been increasing interest in quality measurement using quality indicators in the last few years at international conferences, in policies, and in the literature. Moreover, in 2011, the European Association for Palliative Care created a task force on patient-reported outcome measurement including quality indicators to harmonize the approaches to quality measurement in palliative care. 13,14

Therefore, it is likely that new sets of quality indicators will have been developed and that some of the methodological characteristics of the indicators in the previous review will have been explored in more detail. In view of the above-mentioned recommendation and our expectations that the increased attention would result in new developments in this area, we proposed to update the systematic review by Pasman et al.⁹

This article presents an updated systematic review describing the state of the art of quality indicators for palliative care. We describe 1) the extent to which these quality indicators cover the eight domains of palliative care identified by the NCP; 2) whether the quality indicators cover outcomes, processes, or structure of palliative care; and 3) the methodological characteristics of the quality indicators. We were particularly interested in any new developments,

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