

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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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.¹ Quality indicators are explicitly defined measurable items referring to the outcomes, processes, or structure of care.^{2,3} 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.²

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.⁹ 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,

especially developments that overcame any of the shortcomings found by Pasman et al.

Methods

Data Sources and Searches

All references included in the review by Pasman et al. also were included in this updated review. To identify new relevant literature, searches were performed in the same databases as in the Pasman review: PubMed, PsycINFO (via OvidSP), Embase.com, and CINAHL (via EBSCO). The search period ran from the inception of the databases to October 7, 2011. No limitations regarding language were applied. Controlled terms from MeSH in PubMed, thesaurus terms from PsycINFO, Emtree in Embase.com, CINAHL Headings in CINAHL, and free-text terms were used. Search terms expressing palliative care were combined with search terms comprising quality indicators. The PubMed search strategy is displayed in [Appendix I](#) (available at jpsmjournals.com); the search strategies performed in the other databases were comparable and are available on request.

Both the results of the previous searches by Pasman et al. and new searches were entered in a Reference Manager database and were checked for duplicates. All single references were included for the further selection process.

Inclusion Criteria and Study Selection

Newly identified references were eligible for inclusion if they met the following inclusion criteria, also used in the review by Pasman et al.: 1) the publication describes the development process and/or characteristics of quality indicators developed specifically for palliative care provided by care organizations or professionals and 2) numerators and denominators are defined for the quality indicators, or the numerators and denominators can be deduced directly from the descriptions of the quality indicators, or performance standards are given. Literature in a language other than English could be included in this systematic review if an English translation of the indicators was available (either included in the literature or available on request). Editorials, letters to the editor, comments, and narrative case reports were excluded. Indicators focusing on national palliative care policy or the organization of

palliative care at a national level (e.g., Ahmedzai et al.¹⁵) also were excluded. Publications describing the application of existing quality indicators in clinical practice or reviews of several (sets of) quality indicators without any new developments in addition to the previous review by Pasman et al. were not included in this review.

Newly identified references were screened by two reviewers independently (K. L. and J. C. or S. J. J. C. and M. L. D. R.) in a two-stage inclusion process. In the first stage, references were screened independently by title and abstract. All references deemed eligible for inclusion proceeded to the second selection stage, in which two reviewers independently examined the remaining references by reading the full texts. Any discrepancies between reviewers' selections were discussed until consensus was obtained, or else one of the other review authors (A. L. F.) was consulted. The reference lists of all publications selected in the second stage were checked to identify any relevant publications that had not been found in the computerized searches.

Data Extraction

The data extraction form designed by Pasman et al.⁹ was used to extract relevant data from the included literature. The extracted information included a general description of the quality indicator, the target population, the applicable setting, and the type of quality indicator (whether it describes an outcome, a process, or a structure of palliative care). If relevant information regarding characteristics was lacking, the publication authors were contacted for additional information. If multiple publications dealt with the same indicator set, the descriptions of the quality indicators in the most recent publication were used for this review. Data extraction forms were completed by two reviewers (K. L. and M. L. D. R. or S. J. J. C. and M. L. D. R.) independently. Discrepancies between reviewers were discussed and in those cases in which a consensus could not be reached, one of the other coauthors (A. L. F.) was consulted.

If after completing the extraction forms it seemed that certain individual quality indicators did not fulfill the inclusion criteria described earlier in this section (e.g., numerator and denominator were not defined for this specific indicator), they were not considered

for further analysis. Consequently, not all indicator sets were selected in their entirety.

Subsequently, the quality indicators were categorized by two reviewers independently (K. L. and M. L. D. R. or S. J. J. C. and M. L. D. R.) into the domains of palliative care defined by the NCF.^{4,6,7} These domains are as follows:

1. *Structure and Process of Care* (e.g., organizing training and education for professionals; providing continuity of care)
2. *Physical Aspects of Care* (e.g., measuring and documenting pain and other symptoms; assessing and managing symptoms and side effects)
3. *Psychological and Psychiatric Aspects of Care* (e.g., measuring, documenting, and managing anxiety, depression, and other psychological symptoms; assessing and managing the psychological reactions of patients/families)
4. *Social Aspects of Care* (e.g., conducting regular patient/family care conferences to provide information, discuss goals of care, and offer support to patient or family; developing and implementing comprehensive social care plans)
5. *Spiritual, Religious, and Existential Aspects of Care* (e.g., providing information about availability of spiritual care services to patient or family)
6. *Cultural Aspects of Care* (e.g., incorporating cultural assessments such as the locus of decision making and preferences of patient or family regarding the disclosure of information and truth telling, language, and rituals)
7. *Care of the Imminently Dying Patient* (e.g., recognizing and documenting the transition to the active dying phase; ascertaining and documenting patient/family wishes about the place of death; implementing a bereavement care plan)
8. *Ethical and Legal Aspects of Care* (e.g., documenting patient/surrogate preferences for care goals, treatment options and the care setting; making advance directives; promoting advance care planning)

Methodological Assessment

As in the previous review,⁹ the quality indicators were assessed methodologically using the

Appraisal of Indicators through Research and Evaluation (AIRE) instrument.¹⁶ This instrument comprises 20 items, subdivided into four categories. Three of these categories were used for the methodological assessment in this review (see Appendix II; available at jpsmjournal.com). The fourth category, “purpose, relevance, and organizational context,” was less relevant for this review because the items in this category reflect the relevance of the quality indicators within a particular context rather than the methodological characteristics. Each item’s score ranges from 1 to 4, where 1 is “strongly disagree” (confident that the criterion has not been fulfilled or no information was available); 2 and 3 are “disagree/agree” (unsure whether the criterion has been fulfilled; answer “agree” or “disagree,” depending on the extent to which the criterion has been fulfilled); and 4 is “strongly agree” (confident that the criterion has been fulfilled).

The AIRE instrument was completed by two of the authors independently (K. L. and M. L. D. R. or S. J. J. C. and M. L. D. R.) for the entire sets of quality indicators rather than for each quality indicator separately, because most publications only gave general information for the set as a whole concerning the development of the quality indicators and supporting evidence.

The scores for each of the three categories were calculated by summing the individual authors’ scores for the items in a category and standardizing this total as a percentage of the maximum possible score for that category. The category scores are independent and, therefore, should not be aggregated into a single total quality score. The maximum possible score for a category was calculated by multiplying the maximum score per item (score of 4) by the number of items in that category (three, three, or nine) and the number of evaluators (two). The minimum possible score was calculated at the same time by using the minimum score per item (score of 1).

The standardized category score is the total score per category, minus the minimum possible score for that category, and divided by the maximum possible score minus the minimum possible score times 100%. This standardized score ranges between 0% and 100%, with a higher score indicating a higher methodological level.¹⁶

Results

Search Results

In addition to the 650 references found by Pasman et al. in 2007, 435 new unique and potentially relevant references were found in 2011 for this update. Initial screening of these 435 new results based on the title and abstract resulted in 78 publications for a full-text read. Ultimately, nine of these 78 publications met the inclusion criteria.^{17–25} The most common reason for exclusion was that neither numerators and denominators nor a performance standard were given (Inclusion Criterion 2). Four additional publications^{26–29} were included after reference tracking of the selected publications and contacting the authors if information was lacking. Hence, a total of 13 new publications have been included in this review, in addition to the 21 publications (16 originally identified, plus five used for the methodological analysis) identified by Pasman et al. in 2007.^{30–50} A flow chart of the selection stages is presented in Fig. 1.

These 13 new publications described a total of nine new sets, in addition to the eight sets of quality indicators found by Pasman et al., as presented in Table 1 (the new sets are marked with ^{NEW} in Table 1). Eight of these sets are completely new, whereas one set²¹ is an adapted and shortened version of a set found in the previous review.

The new sets of quality indicators contained 187 partly overlapping quality indicators, in addition to the 142 quality indicators found in the previous review. This resulted in 326 unique indicators (three indicators were identical to indicators found in the previous review), described in more detail in Appendix III (available at jpsmjournal.com).

General Overview of the Quality Indicator Sets Found

Most sets in the original review were developed in the U.S., whereas the new sets included some developed in The Netherlands, Japan, and the U.K. (Table 1). Various palliative care settings and patient populations are covered. Concerning palliative cancer care, three new sets^{18–20,22,23,34} were found in addition to the two sets found in the previous review.^{32,33,49,50} One set was found in the previous review with regard to end-of-life care for the vulnerable elderly;^{30,38,42,47,49} it

subsequently was shortened and adapted for use in The Netherlands.²¹ Concerning palliative care in a hospice setting, two sets were found: one set had already been found in the previous review,⁵⁰ but this update revealed an additional set focusing on hospice or palliative care.²⁵ In the previous review, one set was found for end-of-life care in intensive care units,^{39,40} palliative nursing home care,³⁵ home palliative care,⁴¹ and hospital-based palliative care⁴⁶ (one set for each of the four settings).

In addition, four new sets were found with a relatively broad focus. One set applies to all settings in which palliative care is provided for adult patients and was developed in The Netherlands,^{17,29} one set was developed for use in a variety of specialist care settings in Australia,^{24,28} and two sets focus on palliative care in several settings in the U.K.^{26,27}

Quality Indicators Per Domain of Palliative Care

All the eight domains of palliative care as defined by the NCP^{4,6,7} were covered by the quality indicators found in either the original review or updated searches. However, coverage is not equally distributed across the domains (Table 2). The domains with the most indicators were Physical Aspects of Care (112 quality indicators) and Structure and Process of Care (95 indicators). Most quality indicators dealing with Physical Aspects of Care concerned the assessment and treatment of pain or dyspnea (e.g., Lorenz et al. 2009, Miyashita et al., Keay et al., Schenck et al., and Twaddle et al.; Table 1). In the Structure and Process of Care domain, most quality indicators focused on communication with patients and family and information given to them, for example, concerning prognosis (e.g., Yabroff et al.; Table 1).

A relatively large number of quality indicators also was found (44 indicators) for Ethical and Legal Aspects of Care, mostly concerning advance care planning (e.g., Lorenz et al. 2007 and ELCQuA; Table 1). For Psychological and Psychiatric Aspects of Care, 33 quality indicators were found, concerning issues such as anxiety and depression and the presence of emotional support (e.g., NHPCO and Claessen et al.; Table 1). Twenty-six were found for the domain Care of the

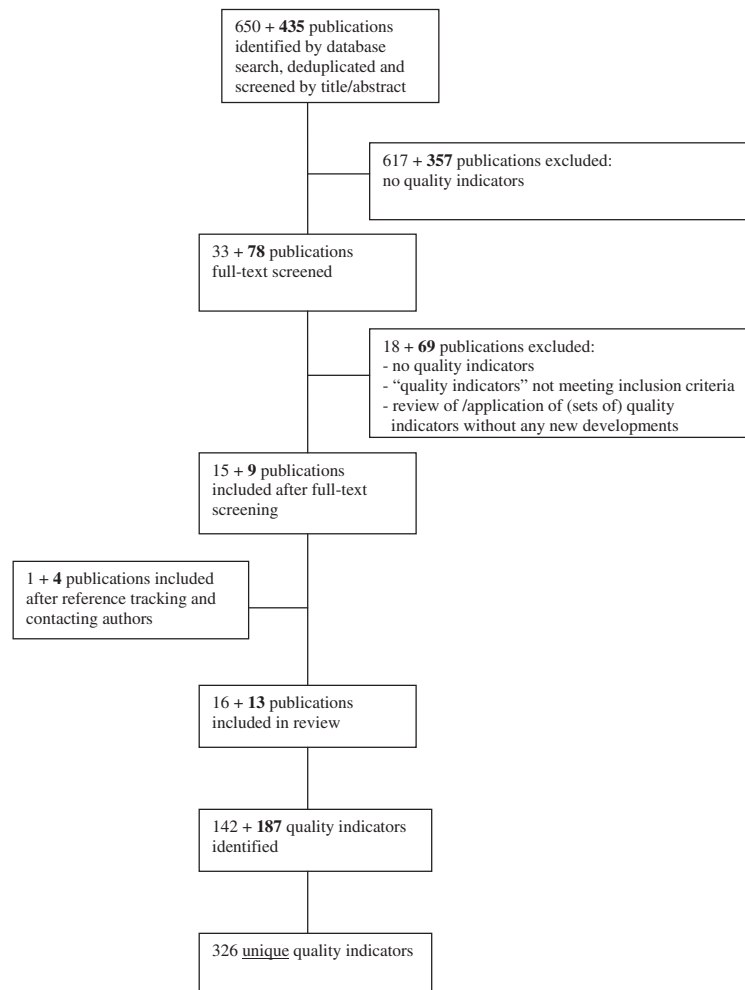


Fig. 1. Flow chart of the literature search. First number marks the results found in the original review by Pasman et al.⁹ and second number (in bold) indicates the additional results found in this review.

Imminently Dying Patient, mainly concerning the aggressiveness of care and bereavement (e.g., Earle et al. and Grunfeld et al.; Table 1). For Social Aspects of Care, 15 quality indicators were found; there were six for Spiritual, Religious, and Existential Aspects of Care and only one for Cultural Aspects of Care.

Outcome, Process, or Structure Quality Indicators

Most quality indicators (199 indicators) concerned the process of care. They mainly addressed the documentation of the care that was actually provided to/received by the patient (Table 2) (e.g., van der Ploeg; Table 1). Also, a substantial number of outcome

indicators was found (117 indicators). Only 22 indicators for the structure of palliative care were found, with 14 indicators coming from one set.²⁶

Methodological Characteristics of Quality Indicators

There was wide variation in the information presented about the methodological characteristics of the identified sets of quality indicators. Some indicator sets and their development process were described in detail, with a clear definition of numerators, denominators, and/or performance standards, whereas the other indicator sets were lacking more detailed information on methodology (Table 3). Furthermore, these sets differ in the extent to

Table 1
Characteristics of Quality Indicator Sets

First Author, Year, Country, References	Population	Setting	Number of Indicators: Total and Per Type	Number of Indicators Per Domain	Example of Indicator (Type/Domain)
Earle, 2006 USA, ^{32,33,50}	Patients with cancer	Not specified	Total: 7 Outcome: 0 Process: 7 Structure: 0	Domain 1: 3 Domain 2: 0 Domain 3: 0 Domain 4: 0 Domain 5: 0 Domain 6: 0 Domain 7: 4 Domain 8: 0	“Proportion with more than one hospitalization in the last 30 days of life” Numerator: Patients who died from cancer and had more than one hospitalization in the last 30 days of life Denominator: Patients who died from cancer Performance standard: <4% (Process/Domain 7)
^{NEW} Grunfeld, 2008, USA, ^{18,34}	Cancer patients in their last six months of life	All settings where end-of-life care is provided	Total: 10 Outcome: 4 Process: 6 Structure: 0	Domain 1: 4 Domain 2: 2 Domain 3: 0 Domain 4: 0 Domain 5: 0 Domain 6: 0 Domain 7: 4 Domain 8: 0	“Enrollment in palliative care within three days of death” Numerator: Number of cases enrolled in palliative care within three days prior to death Denominator: All cases enrolled in palliative care (Process/Domain 7)
Yabroff, 2004, USA, ⁴⁹	Patients with cancer (as prototype)	Not specified	Total: 10 Outcome: 5 Process: 5 Structure: 0	Domain 1: 8 Domain 2: 1 Domain 3: 1 Domain 4: 0 Domain 5: 0 Domain 6: 0 Domain 7: 0 Domain 8: 0	“Percentage of patients and family/caregivers within health facilities or systems that understand and are satisfied with provider communication about prognosis” No further specifications (Outcome/Domain 1)
^{NEW} Lorenz, 2009, USA, ^{22,23}	Adults with cancer	Major clinical settings in which cancer patients seek care, including general practice and oncology settings	Total: 41 Outcome: 0 Process: 41 Structure: 0	Domain 1: 2 Domain 2: 33 Domain 3: 3 Domain 4: 0 Domain 5: 0 Domain 6: 0 Domain 7: 0 Domain 8: 3	“IF a cancer patient is admitted to a hospital, THEN there should be screening for the presence or absence of pain” No further specifications (Process/Domain 2)
^{NEW} Miyashita, 2008, Japan, ^{19,20}	Terminal cancer patients and their family members	All clinical settings, including general wards, palliative care units, and home care	Total: 37 Outcome: 19 Process: 18 Structure: 0	Domain 1: 6 Domain 2: 8 Domain 3: 4 Domain 4: 5 Domain 5: 2 Domain 6: 1 Domain 7: 1 Domain 8: 10	“Symptom control: Physician’s prescription order for dyspnea” Numerator: Number of patients for whom this indicator was documented on admission or within the last two weeks of the hospitalization Denominator: All patients who died (retrospectively identified) (Process/Domain 2)

Peruselli, 1997, Italy, ⁴¹	Terminal patients	Home care	Total: 54 Outcome: 43 Process: 11 Structure: 0	Domain 1: 17 Domain 2: 18 Domain 3: 14 Domain 4: 3 Domain 5: 0 Domain 6: 0 Domain 7: 2 Domain 8: 0	<p>“Palliative care services must meet the physical, psychological, social, and spiritual needs of patients”</p> <p>Numerator: Number of patients with global scores for fatigue (TIQ scale) not increased over initial score during final week of care (if initial score on the same scale >25)</p> <p>Denominator: Total patients × 100</p> <p>Performance standard: 75% (Outcome/Domain 2)</p>
Keay, 1994, USA, ³⁵	Terminally ill in nursing homes	Nursing home	Total: 7 Outcome: 1 ^a Process: 7 Structure: 0	Domain 1: 0 Domain 2: 3 Domain 3: 1 Domain 4: 0 Domain 5: 0 Domain 6: 0 Domain 7: 1 Domain 8: 2	<p>“If a terminally ill patient is reported to be in pain, this is addressed by the physician and active attempts are made to reduce pain”</p> <p>Exclusion: Minor pain symptoms in cognitively intact patients</p> <p>Performance standard: 100% (Process + Outcome/Domain 2)</p>
Lorenz, 2007, USA, ^{30,36,38,42,47}	Vulnerable elderly	Not specified ^b	Total: 23 Outcome: 0 Process: 23 Structure: 0	Domain 1: 2 Domain 2: 8 Domain 3: 1 Domain 4: 1 Domain 5: 0 Domain 6: 0 Domain 7: 1 Domain 8: 10	<p>“If a vulnerable elder has documented treatment preferences to withhold or withdraw life-sustaining treatment (e.g., DNR order, no tube feeding, and no hospital transfer), then these treatment preferences should be followed, because medical care should aim to be consistent with a patient’s preferences”</p> <p>No further specifications (Process/Domain 8)</p>
^{NEW} van der Ploeg, 2008, The Netherlands, ²¹	Vulnerable elders Adapted and shortened version of the set by Lorenz et al. 2007	Care for vulnerable elders in general; this publication is currently focusing on care provided by the general practitioner	Total: 6 ^c Outcome: 2 Process: 4 Structure: 0	Domain 1: 0 Domain 2: 4 Domain 3: 2 Domain 4: 1 Domain 5: 0 Domain 6: 0 Domain 7: 1 Domain 8: 1	<p>“If a vulnerable elder dies with a progressive incurable disease (e.g., metastatic cancer or dementia), then there should be evidence within six months before death that they received a comprehensive assessment including:</p> <ul style="list-style-type: none"> • Pain; • Anxiety and depression; • Vomiting and dyspnea; • Spiritual and existential concerns; • Caregiver burdens/need for practical assistance; • Wishes concerning medical treatment and care at the end of life; a discussion about and if possible the determination of a surrogate decision maker” <p>No further specifications (Process/ Domains 2,3,4, and 8)</p>

(Continued)

Table 1
Continued

First Author, Year, Country, References	Population	Setting	Number of Indicators: Total and Per Type	Number of Indicators Per Domain	Example of Indicator (Type/Domain)
National Hospice and Palliative Care Organization (NHPCO), 2006, USA, ⁵⁰	Patients enrolled in hospice program	Not specified	Total: 8 Outcome: 4 Process: 4 Structure: 0	Domain 1: 1 Domain 2: 3 Domain 3: 2 Domain 4: 0 Domain 5: 0 Domain 6: 0 Domain 7: 2 Domain 8: 0	“Family evaluation of hospice care: symptom management Questions (to family): Although under the care of hospice, did the patient have any feelings of anxiety or sadness? How much help in dealing with these feelings did the patient receive?” Numerator: Those who received too much or too little help concerning anxiety/sadness Denominator: Those who experience anxiety/sadness Exclusion: Patients who are not enrolled in a hospice program or have disenrolled from a hospice program. Live discharged are excluded (Outcome/Domain 3)
^{NEW} Schenck, 2010, USA, ²⁵	Patients in hospice or palliative care	Hospice or palliative care	Total: 28 Outcome: 10 ^a Process: 19 Structure: 0	Domain 1: 2 Domain 2: 17 Domain 3: 3 Domain 4: 0 Domain 5: 1 Domain 6: 0 Domain 7: 0 Domain 8: 5	“For patients who screened positive for pain, the percent with any treatment within one day of screening” Numerator: Number of patients with (0 ≤ pain treatment time ≤ 1) and (pain treatment = “Y”) [pain treatment time = date of treatment – pain assessment date] Denominator: Patients with pain (Process/Domain 2)
Nelson, 2006 and Mularski, 2006, USA, ^{39,40,d}	Critically ill	Intensive care units (ICU)	Total: 21 ^d Outcome: 2 ^a Process: 15 Structure: 5	Domain 1: 9 Domain 2: 5 Domain 3: 0 Domain 4: 2 Domain 5: 1 Domain 6: 0 Domain 7: 1 Domain 8: 4	“Documentation of offering of psychosocial support within the first 72 hours of admission to the ICU” Numerator: Total number of patients in the ICU for >72 hours with psychosocial support offered to the patient or family by any team member Denominator: Total number of patients in the ICU for >72 hours Exclusion: Comatose patients (e.g., Glasgow Coma Score of 2 or 3) with no family member or friend identified (Process/Domain 4)

Twaddle, 2007, USA, ⁴⁶	Patients in hospitals	Hospital	Total: 11 Outcome: 2 Process: 9 Structure: 0	Domain 1: 4 Domain 2: 6 Domain 3: 1 Domain 4: 0 Domain 5: 0 Domain 6: 0 Domain 7: 0 Domain 8: 0	“Percentage of all patients with documentation of dyspnea assessment within 48 hours of admission” Performance standard: 90% (Process/ Domain 2)
^{NEW} Claessen, 2011, The Netherlands, ^{17,29}	Adult patients receiving palliative care	All settings in which palliative care is being provided for adult patients in the Netherlands	Total: 11 Outcome: 10 Process: 1 Structure: 0	Domain 1: 1 Domain 2: 4 Domain 3: 2 Domain 4: 0 Domain 5: 2 Domain 6: 0 Domain 7: 1 Domain 8: 1	“Care for psychosocial well-being of patients: percentage of patients who feel depressed” Numerator: The number of patients with a feeling depressed score of 4 or more on a NRS (average over three days) Denominator: The total number of patients for whom this indicator is measured Exclusion: Patients with moderate to (very) severe cognitive impairments, young children, psychiatric and/or confused patients, and comatose and deeply sedated patients (Outcome/ Domain 3)
^{NEW} Eagar, 2010, Australia, ^{24,28}	Not specified	Specialist palliative care settings	Total: 3 Outcome: 2 Process: 0 Structure: 1	Domain 1: 2 Domain 2: 1 Domain 3: 0 Domain 4: 0 Domain 5: 0 Domain 6: 0 Domain 7: 0 Domain 8: 0	“The percentage of patients and their family members or carers, who have contact with the palliative care service within 48 hours, taking into account the patient’s phase and functional status” No further specifications (Structure/ Domain 1)
^{NEW} Quality Markers, 2009, U.K., ²⁶	Not specified	Primary care, acute hospitals, community hospitals, care homes, specialist palliative care inpatient facilities, providers of specialist end-of-life care services in the community, district/community nursing services, ambulance services, out of hours medical services ^e	Total: 34 Outcome: 9 Process: 11 Structure: 14	Domain 1: 23 Domain 2: 0 Domain 3: 0 Domain 4: 2 Domain 5: 0 Domain 6: 0 Domain 7: 5 Domain 8: 4	“Proportion of individuals whose preferred place for care has been recorded” No further specifications (Outcome/ Domain 8)
^{NEW} End of Life Care Quality Assessment (ELCQuA), 2011, U.K., ²⁷	Not specified	Commissioners, primary care, acute hospitals, community services, including community hospitals, care homes, specialist palliative care inpatient services,	Total: 18 ^f Outcome: 4 ^g Process: 13 Structure: 3	Domain 1: 11 Domain 2: 0 Domain 3: 0 Domain 4: 1 Domain 5: 0	“Individuals have an agreed care plan” Numerator: Number of deceased patients with care plan in place. Denominator: Total deaths for same catchment and time period

(Continued)

Table 1
Continued

First Author, Year, Country, References	Population	Setting	Number of Indicators: Total and Per Type		Example of Indicator (Type/Domain)
			Per Domain	Number of Indicators	
	specialist palliative care		Domain 6: 0	Domain 6: 0	Performance standard: Care plans in place for all patients approaching the end of life (Process/Domain 8)
	community services, ambulance services, out of hours services ^e		Domain 7: 3	Domain 7: 3	
			Domain 8: 4	Domain 8: 4	

TIQ = therapy impact questionnaire; DNR = Do Not Resuscitate order; NRS = numeric rating scale.

¹Indicates that these quality indicator sets have been found in this update.

²One indicator contained outcome and process of care.

³Saliba et al.⁴² tested the feasibility of a selection of the quality indicators for nursing home residents.

⁴One indicator suits four NCP categories.

⁵Both Nelson et al. and Mularski et al. used the same preliminary set of quality indicators for the ICU³¹ but partly selected different quality indicators. The total number of quality indicators in this set is the total of both sets.

⁶Not all indicators apply to all settings.

⁷Two indicators suit two NCP categories.

⁸Two indicators contained outcome and process of care.

which they have been tested in daily practice. For most of the indicator sets, the highest scores were obtained for the items “scientific evidence” and “stakeholder involvement” and the lowest scores for the item “additional evidence” and “formulation and usage.” The sets by Schenck et al.²⁵ and Earle et al.^{32,33,50} had high scores in all three categories; the sets by Peruselli et al.⁴¹ and Quality Markers²⁶ had the lowest scores. Items that scored particularly poorly were “the indicator has been formally endorsed,” “the supporting evidence has been critically appraised,” “the indicator has sufficient discriminative power,” and “specific instructions for presenting and interpreting the indicator results are provided.” These poor scores also were found in the original review (data not shown).

Discussion

Seventeen sets of quality indicators for palliative care were found in this systematic review. These sets mostly concerned specific patient groups (e.g., cancer patients and elderly people) or specific health care settings (e.g., hospice, intensive care unit, home care, and hospital); a few sets focus on all palliative care settings within one country. The sets contained a total of 326 unique but strongly overlapping indicators, covering all domains of palliative care defined by the NCP. Although structure, process, and outcome indicators were represented in these quality indicator sets, most indicators referred to the process or outcome of care and only a few to the structure of care. The methodological characteristics of the quality indicators vary widely, with some indicator sets and their development process being described in detail and others lacking this information. Furthermore, some of the new indicator sets were developed outside the U.S., whereas most sets in the previous review were developed within the U.S.

Domains of Palliative Care

All eight domains defined by the NCP were covered by the quality indicators identified in this review, but only five of these domains had a substantial number of indicators (Structure and Process of Care, Physical Aspects of Care, Psychological and Psychiatric Aspects of

Table 2
Number of Quality Indicators Identified Per Domain According to the Type of Indicator

Domains	Type of Indicator			Total
	Outcome	Process	Structure	
1: Structure and Process of Care ^{a,b}	20	55	21	95 ^a
2: Physical Aspects of Care ^{b,c}	41	74	0	112 ^c
3: Psychological and Psychiatric Aspects of Care ^b	21	12	0	33
4: Social Aspects of Care ^b	4	11	0	15
5: Spiritual, Religious, and Existential Aspects of Care	5	1	0	6
6: Cultural Aspects of Care	1	0	0	1
7: Care of the Imminently Dying Patient ^{a,b}	9	17	1	26 ^a
8: Ethical and Legal Aspects of Care ^{a,b}	16	29	0	44 ^a
Total	117	199	22	326 ^{a,b,c}

^aOne indicator contained outcome and process of care.

^bSome indicators suit several domains: Indicator no.30 (see Appendix III available at jpsmjournals.com) suits Domains 1 and 8. Indicator no. 200 suits Domains 2, 3, 4, and 8. Indicator no. 284 suits Domains 7 and 8.

^cThree indicators contained outcome and process of care.

Care, Care of the Imminently Dying Patient, and Ethical Aspects of Care). The domains Social Aspects of Care and Spiritual, Religious, and Existential Aspects of Care were covered by 15 and six indicators, respectively, and Cultural Aspects of Care was covered by only one quality indicator identified in this review.

Although Pasman et al.⁹ suggested that extra attention should be paid to the development of quality indicators in these latter domains,

so far no such efforts have been made. Only one set of quality indicators in Japan¹⁹ covered all eight domains. However, for some indicators, it can be debated as to which domain they belong. As pointed out in Table 2, some indicators suit more than one domain. This unequal distribution of the indicators across the eight domains also could be indicative of how daily palliative care practice pays more attention to themes such as symptom control

Table 3
Methodological Characteristics of Sets of Quality Indicators (AIRE Instrument)

Methodological Characteristics	Category 1: Stakeholder Involvement, %	Category 2: Scientific Evidence, %	Category 3: Additional Evidence, Formulation and Usage, %
Palliative cancer care (Earle et al.) ^{32,33,50}	89	67	74
^{NEW} Palliative cancer care (Grunfeld et al.) ^{18,34}	83	78	39
Palliative cancer care (Yabroff et al.) ⁴⁹	22	56	17
^{NEW} Palliative cancer care (Lorenz et al.) ^{22,23}	61	89	57
^{NEW} Palliative cancer care (Miyashita et al.) ^{19,20}	56	28	31
Family evaluation of hospice care (NHPCO) ^{44,45,50}	78	72	46
^{NEW} Hospice and palliative care (Schenck et al.) ²⁵	89	89	63
Vulnerable elderly in end-of-life care (Lorenz et al.) ^{a,30,38,42,43,47,48}	67	100	44
^{NEW} Vulnerable elderly in end-of-life care (van der Ploeg et al.) ²¹	50	89	22
ICU end-of-life care (Nelson et al.) ^{a,b,31,40}	67	83	59
ICU end-of-life care (Mularski et al.) ^{a,b,31,39}	67	39	33
Palliative nursing home care (Keay et al.) ³⁵	33	61	15
Home palliative care (Peruselli et al.) ⁴¹	17	11	28
Hospital-based palliative care (Twaddle et al.) ⁴⁶	39	33	21
^{NEW} All settings for palliative care in The Netherlands (Claessen et al.) ^{17,29}	89	89	43
^{NEW} Specialist palliative care (Eagar et al.) ^{24,28}	22	11	48
^{NEW} Several settings for palliative care in the U.K. (Quality Markers) ²⁶	44	11	11
^{NEW} Several settings for palliative care in the U.K. (End of Life Care Quality Assessment) ²⁷	50	33	22

AIRE = Appraisal of Indicators through Research and Evaluation Instrument.¹⁶

^aRefs.^{31,43-45,48} were used for completing the AIRE Instrument because they contain additional information about the development of the quality indicators that is necessary for completing the instrument.

^bBoth Nelson et al. and Mularski et al. used the same preliminary set of quality indicators for the ICU³¹ but partly selected different quality indicators. In the publication by Nelson et al., some of the quality indicators are presented in more detail. Therefore, we decided to fill in the AIRE Instrument for each publication separately.

and communication and less to psychosocial or spiritual support. The relative underrepresentation of some domains does not necessarily need to be seen as problematic. However, if palliative care is claiming to cover these aspects of care, adequate indicators are necessary to monitor quality.

Types of Quality Indicators

Most of the sets of quality indicators reviewed in this article mainly comprised process indicators, most often addressing the documentation of care. Three of the 17 sets identified consisted only of process indicators,^{22,32,33,38,50} whereas two authors^{17,41} primarily focused on the outcome of care. Only three sets contained all three types of quality indicators.^{26,27,39,40} In the literature concerning quality indicators, there is some disagreement about which indicator type is most suitable for the assessment of the quality of palliative care. Until recently, most authors gave preference to process indicators.^{51,52} Process indicators, like structure indicators, are inexpensive and easy to measure because the information needed can be obtained from medical charts or administrative databases. Therefore, no risk adjustment is needed. However, the disadvantage is that such databases can be limited in providing the right information for a good quality assessment, especially in documenting issues such as communication, patient-reported outcomes, or preferences.⁵³ Precise information on these subjects can only be obtained from patients themselves or their families¹⁷ by measuring outcome indicators. Besides the fact that these measurements may cause practical issues or be burdensome to patients, comparing quality of care measured through outcome indicators among different health care settings and different professionals is complicated, and adjustments for case-mix differences need to be calculated.⁵⁴

In most situations, a quality indicator set needs to be broad and comprehensive, that is, referring to all types of patients and institutions; hence, all three types of indicators should be taken into account. In some cases, for example, when being assigned by the government, the choice can be made to limit the number of quality indicators being developed, and it can be desirable to focus particularly on outcome indicators. Nevertheless, several authors suggest that a combination of structure,

process, and outcome indicators may be most appropriate to measure the quality of palliative care.^{2,4,53,55–57}

Developments Since the 2007 Review

Since the last review in 2007, eight completely new sets have been developed and one adapted and shortened version of an existing set of quality indicators for palliative care. This means that as many indicator sets were developed in the four years between reviews as was the case before 2007. Moreover, the number of quality indicators has more than doubled. Quality assessment of palliative care by quality indicators has achieved growing attention internationally. Whereas most sets in the original review were developed in the U.S., only two of the eight completely new sets were developed there; the others were developed in The Netherlands, the U.K., Japan, and Australia. It can be questioned whether it is necessary to continue developing completely new sets of quality indicators for palliative care. When taking a closer look at all the quality indicators found in the two reviews, it is evident that there is considerable overlap in the content of indicators and indicator sets. Therefore, it is recommended that initiatives to assess the quality of palliative care within a country should start from the existing quality indicator sets found in the literature and adapt them by means of expert consultations and practical tests.

Methodological Characteristics of Quality Indicators

The indicator sets studied in this review differed in the quality of their methodology and the information available about their development. Some sets included very detailed information on the developmental process and the definitions of numerators and denominators. Other sets lacked important information on these subjects. The sets by Earle et al.^{6,32,33} and Schenk et al.²⁵ had the highest methodological scores, following the AIRE instrument. The developmental process for these sets was described very precisely and elaborately. Moreover, both these sets are officially accepted by a national organization. These sets with high scores on the AIRE instrument might well be suitable for use in daily palliative practice.⁹ The set by Peruselli et al.⁴¹

and Quality Markers,²⁶ two sets with low scores on the AIRE categories, were not described in any detail, and there was no information on the development process to be found in the literature.

Because the development of evidence-based quality indicators is resource intensive, it may be useful to start from the existing indicators or sets, saving a large amount of work.⁵⁸ Although the transferability of quality indicators between countries is limited, indicators can be adapted for use in other countries with differences in professional culture and practice.⁵⁹ However, this does require a proper understanding of the methodological characteristics of the original set. Therefore, publication of the methodological characteristics of quality indicator sets, including an extensive description of the development process, is recommended. Indicator sets without a sound development process (i.e., those sets scoring poorly in a methodological assessment) can still be considered as potential quality indicators. They can be used in other quality assessment initiatives, on the condition that they will be developed further.⁹

Strengths and Limitations of This Systematic Review

This systematic review focuses on the need for quality assessment and the improvement of palliative care using quality indicators. In this field, quality indicators have received relatively little attention so far. A strength of this review is the general approach. Most researchers in palliative care focus on specific target groups and settings such as cancer care or hospice care,¹ whereas in this review, the focus was on all types of patient groups and care settings.

However, this review also has limitations. The systematic searches were conducted in international literature databases mainly consisting of references of scientific peer-reviewed literature. However, some gray literature was found through manual reference tracking and subsequently included when the predefined inclusion criteria were met. Nevertheless, some quality indicators or sets for palliative care have been missed because it is known that quality indicators are not always published.³⁷

Second, the methodological assessment was based on the information retrieved from the publications and on additional information obtained by contacting the authors. Regrettably, the process of developing the indicators was not always described in detail, and the authors did not always respond to a request for additional information. As a result of this limitation and because the AIRE instrument mainly focuses on the development process, the methodological quality of the quality indicator sets described in this article may be underestimated. This may partly account for the rather low scores for some quality indicator sets.

Conclusion

Quality measurement for palliative care using quality indicators has received more attention in the last few years. The developments made are mainly quantitative in nature: a substantial number of new indicators have been developed in this field, with strongly overlapping content. This is in contrast with the quality of the development process, which varies widely: some indicators have not been developed in detail. Further development of some of these indicators is needed for a better quality assessment. The existing evidence-based indicators can be used in other countries after adaptation to different health care systems or care organizations. Therefore, a more consistent and detailed publication of methodological characteristics is needed rather than the development of more new sets of quality indicators. Besides the further methodological development of the existing sets, quality indicators also need to be tested in daily practice to evaluate and improve the quality of care at the end of life. This way, optimal care for palliative care patients and their families can be guaranteed.

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Appendices and Supplementary Data

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