Review Article

Quality Indicators for Palliative Care: A Systematic Review

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Abstract

Research has demonstrated a greater understanding of the needs of terminally ill patients and their families, but it also has been found that the palliative care is not optimal. Because of a lack of quality indicators in palliative care, the quality of the care is often not assessed. The aim of this systematic review was to give an overview of published quality indicators for palliative care in all patient groups and settings, to determine whether these quality indicators cover all domains of palliative care, to describe the different types of quality indicators, and to determine the methodological characteristics of the quality indicators. Relevant studies were identified by searching computerized databases up to December 2007. Publications describing the development process or characteristics of quality indicators for palliative care were selected by two reviewers independently. An additional selection criterion was that numerators and denominators were either defined or could be deduced from the descriptions. The data extraction involved the general description and type of the quality indicator, target population, and applicable setting. We identified 650 publications, of which 16 met the inclusion criteria. These publications described eight sets of quality indicators. These sets contained 142 overlapping quality indicators, covering all but one domain (cultural aspects) of palliative care. Most quality indicators referred to the outcomes or processes of palliative care. The methodological characteristics of the quality indicators varied considerably. We conclude that a substantial number of quality indicators for palliative care are available, but most have not been described in detail. More detailed methodological specifications are needed to accurately monitor the quality of palliative care. J Pain Symptom Manage 2009;38;145–156. © *2009 U.S. Cancer Pain Relief Committee. Published by Elsevier Inc. All rights reserved.*

Key Words

Palliative care, quality of care, quality indicators

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Introduction

Measuring the quality of the care that is provided enables professionals and policy makers to monitor and improve the care. However, to assess the quality of the care, we must first determine what constitutes good quality care. Evidence-based knowledge about professional interventions is important, but is still not available for all care situations. Experts or expert panels also contribute to defining good quality care, and experts (also including patient-experts) also can define which outcomes (e.g., patient symptoms or problems) are relevant for the quality of the care.

Once the main aspects of good quality care are defined, then indicators that reflect good or poor quality care can be formulated to make it possible to evaluate the quality of the care that is provided. Quality indicators are explicitly defined and measurable items referring to the outcomes, processes, or structure of care.[1] These describe the outcome, process, and structure of the care that is required for a particular type of patient or clinical circumstance.[2] Quality indicators are usually described with a numerator, a denominator, and a performance standard. Quality indicators can indicate potential problems (such as overuse or underuse) or good quality care.[1]

In palliative care, quality indicators also may be important to enable us to obtain an indication of the quality of the care that is provided, and subsequently to improve the care where needed.[3,4] Palliative care is defined by the World Health Organization (WHO) as an approach that improves the quality of life of patients and their families facing the problems associated with life-threatening illness through the prevention and relief of suffering by means of early identification and impeccable assessment and treatment of pain and other problems, which are physical, psychosocial, and spiritual.[5] With an aging population, the need for palliative care increases, chronic diseases become more common, and the number of people living with the effects of these diseases will increase. This means that there will be an increasing number of people needing some form of care toward the end of life.[4] Because palliative care focuses more on the quality of life of patients and relatives than on prolonging life, specific quality indicators for palliative care are needed. However, only limited attention has yet been paid to quality indicators for the care that is provided for patients with a life-threatening, incurable illness.[3,4]

The National Consensus Project (NCP) for Quality Palliative Care in the United States has published an overview of domains that are relevant to end-of-life care. The representatives of the NCP defined eight domains covering the WHO definition of palliative care (see the Methods section for a description of these domains). Subsequently, they developed guidelines and defined preferred practices for each domain in an effort to guide improvement in the quality of palliative care. They stated that the next step must be the development, testing, and implementation of quality indicators to make it possible that the quality of the care can be determined, compared, and continually improved.[6–8]

The purpose of this article is to present a systematic review of published quality indicators that have been developed for palliative care regardless of country, clinical setting, or patient group. We describe the extent to which these quality indicators cover the eight domains of palliative care identified by the NCP, whether the quality indicators cover the three different types of quality indicators (outcome, process, and structure indicators), and the methodological characteristics of the quality indicators.

Methods

Data Sources and Searches

Studies were identified by means of searches in the computerized bibliographic databases Medline, PsycINFO, EMBASE, and CINAHL. We searched these databases on December 15, 2007, and applied no limitations with regard to language or year of publication. We combined key words and medical-subject headings for palliative care with key words and medical-subject headings for quality indicators (Appendix 1, available online at www.jpsmjournal.com.). Comparable searches were performed in other databases. Details of these search strategies are available from the authors on request.

Study Selection

Publications were included in this systematic review if the following inclusion criteria were met: 1) the publication describes the development process or characteristics of quality indicators for palliative care; and 2) numerators and denominators are defined for the quality indicators, *or* the numerators and denominators can directly be deduced from the descriptions of the quality indicators, *or* performance standards are given. Editorials, letters to the editor, comments, and narrative case reports were excluded.

The identified references were screened for relevance in our systematic review in two phases by two reviewers independently (A.L.F. and H.R.W.P. or H.E.B. and H.R.W.P.). All references were first screened on the basis of title and abstract, and then the full text of all the selected references was screened for relevance.

The reference lists of all the publications selected in the second phase were checked (also including websites) to identify any relevant publications that had not been found in the computerized search.

Data Extraction

A data extraction form was designed by the authors to describe the quality indicators for palliative care. The extracted information consisted of a general description of the quality indicator, the target population, the applicable setting, and the type of quality indicator (indicator for outcome, process, or structure of care).

We contacted the authors of publications for additional information about characteristics of the quality indicators if the relevant information was lacking. If publications concerned the same project/indicator set, the descriptions of the quality indicators in the most recent publication were used for data extraction.

Two reviewers (H.E.B. and H.R.W.P.) independently completed the data extraction forms for each quality indicator. Any disagreements between the reviewers were resolved by consensus.

Subsequently, two reviewers (L.D. and H.R.W.P.) independently categorized the quality indicators into the domains of palliative care defined by the NCP.[6–8] These domains are:

1. Structure and Process of Care, e.g., organizing training and education for professionals, providing continuity of care, and enabling patients to make informed decisions by educating them.
2. Physical Aspects of Care, e.g., measuring and documenting pain and other symptoms, and assessing and managing symptoms and side effects.
3. Psychological and Psychiatric Aspects of Care, e.g., measuring, documenting, and managing anxiety, depression, and other common psychological symptoms; assessing and managing psychological reactions of patients/families; and offering a grief and bereavement care plan.
4. Social Aspects of Care, e.g., conducting regular patient/family care conferences to provide information, to discuss goals of care, and to offer support to patient or family, and 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 locus of decision making, preferences of patient or family regarding 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 site of death, and implementing a bereavement care plan.
8. Ethical and Legal Aspects of Care, e.g., documenting patient/surrogate preferences for goals of care, treatment options, and setting of care, making advance directives and promoting advanced care planning.

Methodological Assessment

For the methodological assessment of the quality indicators, we used the AIRE Instrument (Appraisal of Indicators through Research and Evaluation), which has recently been designed and validated in The Netherlands.[9] This instrument contains 20 items, subdivided into four categories. We used three of these categories for the methodological assessment of the quality indicators (Appendix 2, available online at www.jpsmjournal.com). The fourth category, "purpose, relevance and organizational context," was less relevant for the review, because the items in this category do not reflect the methodological characteristics of the quality indicators but chiefly the relevance of the quality indicator within a particular context. Each item has a score ranging from 1 to 4: 1—strongly disagree (confident that the criterion has not been fulfilled or no information was available); 2/3—disagree/agree (unsure whether the criterion has been fulfilled; answer "agree" or "disagree," depending on the extent to which the criterion has been fulfilled); 4—strongly agree (confident that the criterion has been fulfilled).

The AIRE Instrument was completed by two of the authors independently (H.E.B. and H.R.W.P.) for a total set of quality indicators instead of for each quality indicator separately, because most publications only gave general information about the development and evidence of the total set of quality indicators.

Scores for each of the three categories were calculated by summing up all the scores of the individual items in a category and standardizing the total as a percentage of the maximum possible score for that category. The scores for the categories are independent, and should not be aggregated into a single quality score. The maximum possible score for a category was calculated by multiplying the maximum score per item (4) by the number of items in that category (3, 3, or 9) and the number of appraisers (2). Similarly, the minimum possible score was calculated by using the minimum score per item (1). The standardized category score is the total score per category, minus the minimum possible score for that category, divided by the maximum possible score, minus the minimum possible score × 100%. The standardized score ranges between 0% and 100%, and a higher score indicates a higher methodological level.[9]

Results

A total of 650 unique, potentially relevant publications were identified in the different databases (341 in Medline, 313 in PsycINFO, 59 in EMBASE, and 150 in CINAHL). Based on the title and the abstract, 33 appeared to fulfill the selection criteria, but after reading the full text of these publications, only 15 met the inclusion criteria. In all cases, the reason for excluding publications was that they did not meet our inclusion criteria, that is, that either the numerators and denominators were defined, *or* the numerators and denominators could directly be deduced from the descriptions of the quality indicators, *or* a performance standard was given.

Reference tracking of the selected publications resulted in one additional publication with quality indicators.[10] Furthermore, we identified five publications[11–15] that contained additional information about the development of the quality indicators described in the publications that had been selected. This resulted in the inclusion of a total of 16 publications (see flowchart in Fig. 1).

The 16 publications concerning quality indicators that were included contained one systematic review focusing on quality indicators for specific symptom management in palliative care and a related evidence report[16,17] and 14 publications in which quality indicators were identified on the basis of the literature and expert panels, and/or quality indicators had been tested in daily practice.

The publications described a total of eight different sets of quality indicators. These eight sets focused on different patient groups and different health care settings: two sets concerned palliative cancer care,[10,18–21] one set concerned vulnerable elderly end-of-life care,[22–25] one set concerned family evaluation of hospice and palliative care,[10] one set concerned intensive care unit (ICU) end-of-life care,[26,27] one set concerned palliative nursing home care,[28] one set concerned home palliative care,[29] and one set concerned hospital-based palliative care[30] (Table 1). Five sets (concerning family evaluation of hospice and palliative care,[10] palliative cancer care,[10,18–20] vulnerable elderly end-of-life care,[22–25] ICU end-of-life care,[27] and hospital-based palliative care[30]) were also (partly) described in the review focusing on quality indicators for specific symptom management in palliative care.[16,17]

The eight sets of quality indicators together contained 142 partly overlapping quality indicators (Appendix 3, available online at www.jpsmjournal.com).

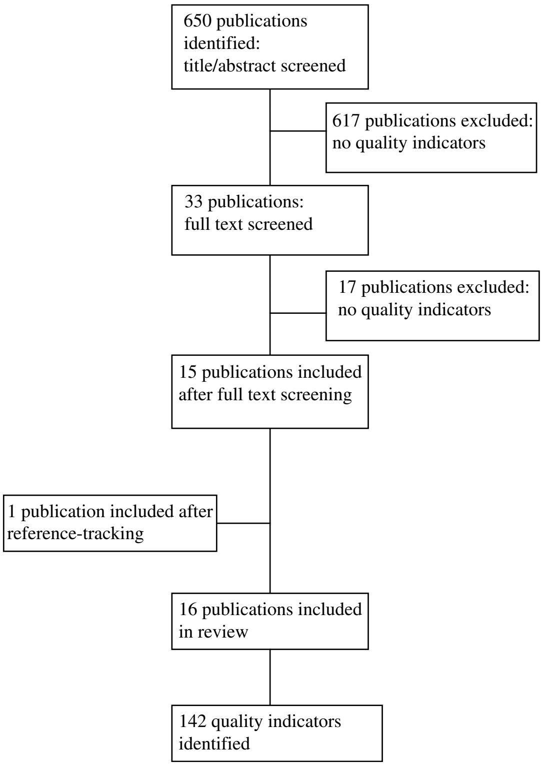

Fig. 1. Flowchart of the literature search.

Quality Indicators per Domain of Palliative Care

The quality indicators covered all but one of the eight domains of palliative care defined by the NCP,[6–8] but were not equally distributed (Table 2). Most quality indicators were found in Domain 1 (Structure and Process of Care) and in Domain 2 (Physical Aspects of Care) (44 quality indicators in each domain). Most of the quality indicators in Domain 1 (31) concerned the Subdomain 1.2 (Process of Care), and mainly focused on communication and information, e.g., with regard to prognosis or goals of care (example: Table 1, Yabroff et al. set). Most of the quality indicators in Domain 2 concerned the assessment of and treatment of pain or dyspnea (example: Table 1, Keay et al., Peruselli et al., and Twaddle et al. sets). These quality indicators were found in all but one quality indicator set, and were overlapping. The third domain, for which a relatively large number of quality indicators were found (20), was Domain 3 (Psychological and Psychiatric Aspects of Care), and concerned, for instance, anxiety or emotional support (example: Table 1, National Hospice and Palliative Care Organization [NHPCO] set). Sixteen quality indicators were found for Domain 8 (Ethical and Legal Aspects of Care), many of which concerned (the documentation of) advance care planning (example: Table 1, Lorenz et al. set). Eleven quality indicators were found for Domain 7 (Care of the Imminently Dying Patient), concerning the aggressiveness of care and bereavement (example: Table 1, Earle et al. set). Lastly, only six quality indicators were found for Domain 4 (Social Aspects of Care), one quality indicator was found for Domain 5 (Spiritual, Religious, and Existential Aspects of Care), and no quality indicators were found for Domain 6 (Cultural Aspects of Care).

Outcome, Process, or Structure Quality Indicators

Most quality indicators (82) reflected the process of care, and mainly concerned documentation of the care provided or documentation of the care preferred by the patient (Table 2). A substantial number of indicators concerned the care that was actually given (example: Table 1, Nelson/Mularski, Lorenz, and Twaddle sets).

A significant number of outcome indicators were also found (57), almost all from one indicator set.[29] The authors used two questionnaires (the Support Team Assessment Schedule [STAS][31] and the Therapy Impact Questionnaire [TIQ]),[32] and formulated two indicators per item on these questionnaires:

> *Number of patients with global scores for each of 9 TIQ scales dropped after 8 days of care;*
>
> *Number of patients with global scores for each of 9 TIQ scales not increased over initial score during final week of care (if initial score on the same scale $>$ 25);*
>
> *Number of patients with score for the 10 STAS items dropped after 8 days of care (if initial score on the same scale $>$ 0);*
>
> *Number of patients with score for the 10 STAS items of 0–1 during final week of life.*

Only five indicators for the structure of palliative care were found, all from one set about ICU care,[26,27] concerning, for instance, the presence of a written policy about visiting

Table 1

Characteristics of Quality Indicator Sets

Author(s), Year, Country, Reference Numbers	Population	Setting	Number of Indicators: Total and per Type	Number of Indicators per Domain	Example of Indicator and Type/Domain
Earle et al., 2006, USA[10,18–20]	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 >1 hospitalization in the last 30 days of life *Denominator*: Patients who died from cancer *Exclusion*: *Performance standard*: <4% (process/Domain 7)
Yabroff et al., 2004, USA[21]	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)
NHPCO, 2006, USA[10]	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); While 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 *Performance standard*: (outcome/Domain 3)
Lorenz et al., 2007, USA[22–25]	Vulnerable elders	Not specified[a]	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	"IF a vulnerable elder is admitted to the hospital or nursing home, THEN within 48 hours of admission, the medical record should contain the patient's surrogate decision maker or documentation of a discussion to identify or search for surrogate decision maker, BECAUSE specification of a surrogate decision maker facilitates decision making for patients at risk of losing decision making capacity" *No further specifications* (process/Domain 8)

Nelson et al., 2006 + Mularski et al., 2006, USA[26,27] [b]	Critically ill	ICUs	Total: 21[b] Outcome: 2[c] 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 2T or 3) with no family member or friend identified. *Performance standard*: (process/Domain 4)
Keay et al., 1994, USA[28]	Terminally ill in nursing homes	Nursing home	Total: 7 Outcome: 1[c] 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	"If terminally ill patient is reported to be in pain, this is addressed by the physician and active attempts are made to reduce pain." *Numerator*: *Denominator*: *Exclusion*: Minor pain symptoms in cognitively intact patients. *Performance standard*: 100% (process + outcome/Domain 2)
Peruselli et al., 1997, Italy[29]	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	"Palliative care services must meet the physical, psychological, social and spiritual needs of patients." *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). *Denominator*: Total patients × 100 *Exclusion*: *Performance standard*: 75% (outcome/Domain 2)
Twaddle et al., 2007, USA[30]	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." *Numerator*: *Denominator*: *Exclusion*: *Performance standard*: 90% (process/Domain 2)

[a] Saliba et al.[23] tested the feasibility of a selection of the quality indicators for nursing home residents.

[b] Nelson et al. and Mularski et al. both used the same preliminary set of quality indicators for the ICU,[11] but partly selected different quality indicators. The total number of quality indicators in this set is the total of both sets.

[c] One indicator contained outcome and process of care.

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

Domains	Type of Indicator Outcome	Process	Structure	Total
1: Structure and Process of Care	13	27	4	44
2: Physical Aspects of Care[a]	26	20	0	44[a]
3: Psychological and Psychiatric Aspects of Care	16	4	0	20
4: Social Aspects of Care	2	4	0	6
5: Spiritual, Religious, and Existential Aspects of Care	0	1	0	1
6: Cultural Aspects of Care	0	0	0	0
7: Care of the Imminently Dying Patient	0	10	1	11
8: Ethical and Legal Aspects of Care	0	16	0	16
Total	57	82	5	142[a]

[a] Two indicators contained outcome and process of care.

patients in the ICU or the presence of a forum for physicians to discuss experiences.

Methodological Characteristics of Quality Indicators

The information about the methodological characteristics of the identified sets of quality indicators varied (Table 3). Some sets had been developed in detail, with clearly defined numerators, denominators, and/or performance standards, whereas the details of other sets were not described. Some sets had been tested in daily practice. Most of the sets had the highest scores for Category 1 (stakeholder involvement) or Category 2 (scientific evidence), and the lowest scores for Category 3 (additional evidence, formulation, and usage). Only the Earle et al. set[10,18–20] had high scores for all three categories, and the Peruselli et al.[29] and Yabroff et al.[21] sets had the lowest scores.

In general, the indicator sets had relatively low scores, especially for Item 1.3 (the indicator has been formally endorsed), Item 2.3 (the supporting evidence has been critically appraised), Item 3.6 (the indicator has sufficient discriminative power) and Item 3.9 (specific instructions for presenting and interpreting the indicator results are provided) (data not shown).

Discussion

The sets of quality indicators for palliative care that we reviewed concerned specific patient groups (cancer, elderly people), or specific health care settings (ICU, nursing home, hospital, home). The sets contained a total of 142 partly overlapping quality indicators,

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

Quality Indicator Set	Category 1: Stakeholder Involvement (%)	Category 2: Scientific Evidence (%)	Category 3: Additional Evidence, Formulation and Usage (%)
Palliative cancer care (Earle et al.)[10,18–20]	89	67	74
Palliative cancer care (Yabroff et al.)[21]	22	56	17
Family evaluation of hospice care (NHPCO)[10,13,14 b]	78	72	46
Vulnerable elderly in end-of-life care (Lorenz et al.)[12,15,22–25 b]	67	100	44
ICU end-of-life care (Nelson et al.)[11,27 b,c]	67	83	59
ICU end-of-life care (Mularski et al.)[11,26 b,c]	67	39	33
Palliative nursing home care (Keay et al.)[28]	33	61	15
Home palliative care (Peruselli et al.)[29]	17	11	28
Hospital-based palliative care (Twaddle et al.)[30]	39	33	21

[a] Appraisal of Indicators through Research and Evaluation (AIRE) Instrument. Available at: www.aire-instrument.com.

[b] References 11–15 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 AIRE Instrument.

[c] Nelson et al. and Mularski et al. both used the same preliminary set of quality indicators for the ICU,[11] but partly selected different quality indicators. In the Nelson et al. publication, some of the quality indictors are presented in more detail. Therefore, we decided to fill in the AIRE Instrument for each publication separately.

which covered all but one domain (Domain 6: Cultural Aspects of Care) of palliative care defined by the NCP in the United States. The three different types of quality indicators are represented in the identified sets of quality indicators. Most of the quality indicators refer to the outcome or process of care, and only a few indicators concern the structure of care. The methodological characteristics of the quality indicator sets vary considerably; some sets are described in detail, whereas for others, there are only general descriptions.

Domains of Palliative Care

Five of the eight domains defined by the NCP are covered by a substantial number of quality indicators (i.e., Structure and Process of Care, Physical Aspects of Care, Psychological and Psychiatric Aspects of Care, Care of the Imminently Dying Patient, and Ethical and Legal Aspects of Care). This may reflect the attention these domains receive in daily practice and in end-of-life research and policies. Cultural Aspects of Care is the only NCP domain of palliative care that is not covered by the quality indicators identified in this review. The NCP chose this domain because of the important influence of culture on serious illness and death.[7] Moreover, only a few quality indicators were found for the domains of the Social Aspects of Care and the Spiritual, Religious, and Existential Aspects of Care. Therefore, extra attention should be paid to the development of quality indicators in these domains.

Several other authors have defined domains of palliative care.[33–36] We used the domains defined by the NCP to structure them, because the NCP is well known among professionals and the domains are described in detail. For some indicators, it can be debated which domain they belong to (such as whether routine pain measurement in terminal care is Domain 2 [Physical Aspects of Care] or Domain 7 [Care of the Imminently Dying Patient]).

Type of Quality Indicator

Most sets of quality indicators for palliative care mainly contain process indicators and often reflect the documentation of care. Only Peruselli et al.[29] developed mainly outcome indicators. There is debate in the literature about which type of quality indicator is most suitable for the assessment of the quality of the care and, in general, preference is given to process indicators.[37–39] The advantages mentioned are: process indicators can be used to provide feedback for quality improvement initiatives; most process indicators only require a definition of the population that is eligible to receive the process and no further risk adjustment is needed; and most process indicators can easily be assessed with information from medical records. However, medical records may not reflect the actual care that is provided.[37] Furthermore, a prerequisite for process indicators is that measures are used for which there is scientific evidence or a formal consensus of experts that the criteria do, indeed, lead to an improvement in health.[38,39] The authors of the quality indicators for vulnerable elders[22] and ICU care[27] deliberately chose to develop process indicators because of the above-mentioned advantages. The Netherlands Health Care Inspectorate[40] deliberately focuses on outcome indicators, because it considers that the outcome is most important and that the process used to achieve the outcome can vary as long as we have no evidence that any specific interventions are better or more effective than other interventions. Mainz stated that, although the providers of care might need detailed information about the process of care for quality improvement purposes, the outcomes of the care may be of major interest to the consumers and financiers of the care.[39]

In palliative care, outcome indicators might be especially important for symptom management, because many palliative care patients suffer from pain and other burdensome symptoms, and the prevention and relief of pain and other symptoms is an important goal in palliative care.[5] However, using outcome indicators is complicated, because adjustment for differences in case mix and other external factors is needed to ensure fair comparisons among institutions or physicians.[41] Furthermore, to measure the outcomes of pain and symptom management, the patients themselves have to be consulted, and this can be burdensome for patients with advanced disease. A combination of process indicators and outcome indicators might, therefore, be most suitable for measuring the quality of palliative care.

Methodological Characteristics of the Quality Indicators

The sets of quality indicators for palliative care that we identified differed in their degree of methodological development, including a clear definition of a numerator and a denominator. The Earle et al. set[10,18–20] and, to a lesser extent, the Lorenz et al.,[12,15,22–25] Nelson et al.,[27] and the NHPCO[10] sets had the highest methodological scores according to the AIRE Instrument. These sets were developed in the greatest detail, and some of them have an official status. The Earle et al. and the NHPCO sets are accepted by the National Quality Forum in the United States, a nonprofit membership organization created to develop and implement a national strategy for health care quality measurement and reporting.[42] The Lorenz et al. set was developed for RAND Health, an authoritative nonprofit institution that helps to improve policy and decision making through research and analysis in the United States.[43] The Yabroff et al.[21] and Peruselli et al.[29] sets, with low methodological scores according to the AIRE Instrument, were not developed in detail, and the development process (reflected by the AIRE items) is not described in the literature. Moreover, these sets were initially not developed as quality indicators but for individual research purposes.

The sets with high AIRE scores might well be suitable for use in daily practice, and the other sets can be considered as potential quality indicators if they are further developed in more detail.

Strengths and Limitations of the Systematic Review

This systematic review focuses on the need to monitor and improve the quality of palliative care. In this respect, the need for quality indicators has received relatively little attention in this field.[3]

A strength of the review is the generic approach. Most researchers in the field of palliative care concentrate on cancer care,[4] but palliative care is much broader than cancer care. Therefore, this review adds to previously published reviews in this field.[16,17,44,45] In addition, our review is complementary to previous reviews, because we assessed the methodological characteristics of the identified quality indicators.

However, this systematic review also has its limitations. First, we only searched for the quality indicators described in the scientific peer-reviewed literature. Therefore, it is likely that there are some quality indicators for palliative care not traced, because it is well known that quality indicators are not always published.[16] Furthermore, we used a rather strict inclusion criterion for quality indicators (numerator and denominated defined or to be deduced). This may have excluded many publications about measuring quality that could ultimately lead to defining quality indicators. Furthermore, many professional organizations and quality institutes started initiatives to measure quality of care,[43,46–50] but these initiatives are not always published in the scientific literature.

Second, the methodological appraisal of the quality indicators was based on information derived from the included publications, but the development process, in particular, was not always described in detail in these publications. This is a serious limitation, because the AIRE Instrument items mainly concern characteristics of the development process. We tried to track down additional information about the development process of quality indicators by contacting the authors, but we were only able to obtain relevant additional information for three sets of quality indicators. This may partially explain why the methodological scores are rather low for some quality indicator sets (such as the Peruselli et al. set[29]).

Conclusion

A substantial number of quality indicators for palliative care are available, but most have not yet been developed in detail. The further development of quality indicators, with detailed methodological specifications, is needed for accurate assessment and monitoring of the quality of palliative care. Furthermore, almost all quality indicators are developed in the United States. Adaptations for use in other countries is needed, because the health care systems vary largely. Because there are many initiatives expected to be developed in this field, including those defining and testing concrete quality indicators, it is expected that quality measurement in palliative care will improve substantially within the coming years.

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Appendix 1

Search Strategy Medline

(((((“Palliative Care”[MeSH] OR ((palliative[ti] OR terminal[ti] OR hospice[ti]) AND care[ti]) OR “Terminal Care”[MeSH:noexp] OR “Life Support Care”[MeSH] OR “Advance Care Planning”[MeSH] OR “Resuscitation Orders”[MeSH] OR “Withholding Treatment”[MeSH] OR “Hospice Care”[MeSH] OR “Hospices”[MeSH] OR “Terminally Ill”[MeSH]))) AND ((“Quality Indicators, Health Care”[MeSH]))) OR ((((“Palliative Care”[MeSH] OR ((palliative[ti] OR terminal[ti] OR hospice[ti]) AND care[ti]) OR “Terminal Care”[MeSH:noexp] OR “Life Support Care”[MeSH] OR “Advance Care Planning”[MeSH] OR “Resuscitation Orders”[MeSH] OR “Withholding Treatment”[MeSH] OR “Hospice Care”[MeSH] OR “Hospices”[MeSH] OR “Terminally Ill”[MeSH]))) AND ((“quality measure” OR “quality measures” OR “quality criterium” OR “quality criteria” OR “quality assessment” OR ((Quality[ti] OR performance[ti] OR satisf*[ti]) AND (indicator*[tw] OR criteri*[tw] OR assess*[ti] OR measur*[ti] OR scale[ti] OR validat*[tw])))))) NOT (letter[pt] OR editorial[pt] OR comment[pt] OR case reports[pt]).

Appendix 2

Categories and Items of the AIRE Instrument[a]

1) Stakeholder Involvement	
Item 1.1	The group developing the indicator includes individuals from relevant professional groups
Item 1.2	Considering the purpose of the indicator, all relevant stakeholders have been involved at some stage of the development process
Item 1.3	The indicator has been formally endorsed
2) Scientific Evidence	
Item 2.1	Systematic methods were used to search for scientific evidence
Item 2.2	The indicator is based on recommendations from an evidence-based guideline
Item 2.3	The supporting evidence has been critically appraised
3) Additional Evidence, Formulation and Usage	
Item 3.1	The numerator and denominator are described in detail
Item 3.2	The target patient population of the indicator is defined clearly
Item 3.3	A strategy for risk adjustment has been considered and described
Item 3.4	The indicator measures what it is intended to measure (validity)
Item 3.5	The indicator measures accurately and consistently (reliability)
Item 3.6	The indicator has sufficient discriminative power
Item 3.7	The indicator has been piloted in practice
Item 3.8	The efforts needed for data collection have been considered
Item 3.9	Specific instructions for presenting and interpreting the indicator results are provided

[a] Appraisal of Indicators through Research and Evaluation (AIRE) Instrument. Available at: www.aire-instrument.com. The complete AIRE Instrument contains a fourth category “Purpose, Relevance and Organizational Context,” which is not used in this review.

Appendix 3

List of Quality Indicators for Palliative Care Identified per Domain

Reference/Year	Description + Type Indicator	Numerator/Denominator/Exclusion/ Performance Standard
Domain 1.1: Structure of care (13x)		
Mularski, 2006 1	Documentation of a policy that allows for unrestricted visitation by family members and friends Structure	**Numerator**: Presence of a policy in the ICU that allows for family and friends to spend time in the patient's room regardless of the time of the day. Policy may include restrictions on the number of visitors at one time or restrictions based on disturbance of other patients or family members or disturbance of the functioning of the ICU. Policies may also include provisions for asking family members or friends to wait in the waiting room during procedures **Denominator**: ICU **Exclusion**: **Performance standard**:
Nelson, 2006 2	Family meeting room: dedicated space for meetings between clinicians and ICU families Structure	Periodic point measurement: presence or absence of room designated for family meetings
Mularski, 2006 3	Documentation of a forum for ICU clinicians to review, discuss, and debrief the experience of caring for dying patients and their families Structure	**Numerator**: Presence of a forum for ICU clinicians to review, discuss, and debrief the experience of caring for dying patients and their families **Denominator**: ICU **Exclusion**: **Performance standard**:
Peruselli, 1997 4	Palliative care service is integrated into the local area health authority and operates at the specific request of the GP and in association with him/her Process	**Numerator**: Number of patients for whom the PCS has had the introductory interview with GP concerning the program objectives **Denominator**: Population served × 100 **Exclusion**: **Performance standard**: 95%
Peruselli, 1997 5	Palliative care service is integrated into the local area health authority and operates at the specific request of the GP and in association with him/her Process	**Numerator**: Number of GPs who have requested the PCS **Denominator**: Total number of GPs in area of health care authority × 100 **Exclusion**: **Performance standard**: 50%
Peruselli, 1997 6	Palliative care service is integrated into the local area health authority and operates at the specific request of the GP and in association with him/her Process	**Numerator**: Number of patients for whom the PCS has had at least 2 interviews with the GP during care process (including preliminary discussion) **Denominator**: Population served **Exclusion**: **Performance standard**: 50%
Peruselli, 1997 7	Home palliative care services reduce admissions to hospital during care period Process	**Numerator**: Number of days in hospital during HPC **Denominator**: Total number of days of HPC care × 100 **Exclusion**: **Performance standard**: 10%
Peruselli, 1997 8	The palliative care service responds rapidly to request for care Process	**Numerator**: Number of patients who received initial visits from a team member within 48 hours of request **Denominator**: Population served × 100 **Exclusion**: **Performance standard**: 95%

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Reference/Year	Description + Type Indicator	Numerator/Denominator/Exclusion/ Performance Standard
Peruselli, 1997 9	Palliative care services are devised for terminal patients during the final stages of life Process	**Numerator**: Number of patients receiving home care for 7 to 90 days **Denominator**: Population served × 100 **Exclusion**: **Performance standard**: 75%
Peruselli, 1997 10	Home palliative care enables patients to stay at home until death Process	**Numerator**: Number of patients dying at home **Denominator**: Total patients × 100 **Exclusion**: **Performance standard**: 95%
Earle, 2006 11	Proportion dying in an acute care setting Process	**Numerator**: Patients who died from cancer in an acute care hospital **Denominator**: Patients who died from cancer **Exclusion**: **Performance standard**: <17%
Earle, 2006 12	Proportion not admitted to hospice Process	**Numerator**: Patients who died from cancer without being admitted to hospice **Denominator**: Patients who died from cancer **Exclusion**: **Performance standard**: <45%
Earle, 2006 13	Proportion admitted to hospice for less than 3 days Process	**Numerator**: Patients who died from cancer and spent fewer than three days in hospice **Denominator**: Patients who died from cancer who were admitted to hospice **Exclusion**: **Performance standard**: <8%
Domain 1.2: Process of care (31x)		
Yabroff, 2004 14	Percentage of patients and family/caregivers within health facilities or systems that understand and are satisfied with provider communication about prognosis Outcome	**Numerator**: **Denominator**: **Exclusion**: **Performance standard**:
Yabroff, 2004 15	Percentage of patients and family/caregivers within and among health facilities or systems that understand and are satisfied with provider communication about risks and benefits or treatment Outcome	**Numerator**: **Denominator**: **Exclusion**: **Performance standard**:
Mularski, 2006 16	Documentation of communication between a physician and a family member or friend of the patient within 24 hours of admission Process	**Numerator**: Patients in the ICU for >24 hours for whom there is documentation that a physician communicated with a family member or friend of the patient in person or by phone **Denominator**: Total number of patients in the ICU for >24 hours for whom a family member or friend can be identified **Exclusion**: Patient for whom no family member or friend can be identified in the first 24 hours **Performance standard**:
Nelson, 2006, Mularski, 2006 17	Interdisciplinary family meeting: percentage of patients with documentation that an interdisciplinary family meeting was conducted on or before day 5 of ICU admission Process	**Numerator**: Number of patients who have documentation in the medical record that an interdisciplinary meeting was held with the patient/family on or before day 5 of ICU admission **Denominator**: Total number of patients with an ICU length of stay **Exclusion** ≥ 5 days **Exclusion**: Patients who were not visited by a family member on or before day 5 of ICU admission AND who lack capacity to participate in such a meeting Patients who refused or whose family refused to participate in a family meeting **Performance standard**:

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Reference/Year	Description + Type Indicator	Numerator/Denominator/Exclusion/ Performance Standard
Nelson, 2006 18	Family information leaflet: percentage of patients whose families received information leaflet (personally) from ICU team member on or before day 1 of ICU admission and action was documented in the medical record Process	**Numerator**: Number of patients with documentation that family received a written information leaflet from an ICU team member **Denominator**: Total number of patients with an ICU length of stay ≥ 5 days **Exclusion**: Patients discharged (or transferred out of the ICU) on or before day 1 of ICU admission Patients expired on or before day 1 of ICU admission Patients who were not visited by a family member on or before day 1 of ICU admission **Performance standard**:
Yabroff, 2004 19	Percentage of patients within and among health facilities or systems where evidence exists to confirm accurate communication about prognosis Process	**Numerator**: **Denominator**: **Exclusion**: **Performance standard**:
Yabroff, 2004 20	Percentage of patients within and among health facilities or systems where evidence exists to confirm accurate communication about risks and benefits of treatment Process	**Numerator**: **Denominator**: **Exclusion**: **Performance standard**:
Yabroff, 2004 21	Percentage of patients and family/caregivers within and among health facilities or systems that understand and are satisfied with their participation in the development of treatment goals Outcome	**Numerator**: **Denominator**: **Exclusion**: **Performance standard**:
Peruselli, 1997 22	Palliative care services must meet the physical, psychological, social and spiritual needs of patients Outcome	**Numerator**: Number of patients with score for patient insight (STAS item) dropped after 8 days of care (if initial score >0) **Denominator**: Total patients x 100 **Exclusion**: **Performance standard**: 75%
Peruselli, 1997 23	Palliative care services must meet the physical, psychological, social and spiritual needs of patients Outcome	**Numerator**: Number of patients with score for patient insight (STAS item) of 0-1 during final week of life **Denominator**: Total patients x 100 **Exclusion**: **Performance standard**: 75%
Peruselli, 1997 24	Palliative care services must meet the physical, psychological, social and spiritual needs of patients Outcome	**Numerator**: Number of patients with score for family insight (STAS item) dropped after 8 days of care (if initial score >0) **Denominator**: Total patients x 100 **Exclusion**: **Performance standard**: 75%
Peruselli, 1997 25	Palliative care services must meet the physical, psychological, social and spiritual needs of patients Outcome	**Numerator**: Number of patients with score for family insight (STAS item) of 0-1 during final week of life **Denominator**: Total patients x 100 **Exclusion**: **Performance standard**: 75%
Peruselli, 1997 26	Home palliative care services are the result of a joint decision taken by the care team and family Process	**Numerator**: Number of patients for whom the PCS had preliminary interview at the outpatient clinic together with the family **Denominator**: Population served x 100 **Exclusion**: **Performance standard**: 95%

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Reference/Year	**Description + Type Indicator**	**Numerator/Denominator/Exclusion/ Performance Standard**
Peruselli, 1997 27	Palliative care services must meet the physical, psychological, social and spiritual needs of patients Outcome	**Numerator**: Number of patients with score for communication between professionals (STAS item) dropped after 8 days of care (if initial score >0) **Denominator**: Total patients x 100 **Exclusion**: **Performance standard**: 75%
Peruselli, 1997 28	Palliative care services must meet the physical, psychological, social and spiritual needs of patients Outcome	**Numerator**: Number of patients with score for communication between professionals (STAS item) of 0-1 during final week of life **Denominator**: Total patients x 100 **Exclusion**: **Performance standard**: 75%
Peruselli, 1997 29	Palliative care services must meet the physical, psychological, social and spiritual needs of patients Outcome	**Numerator**: Number of patients with score for communication professional to patient and family (STAS item) dropped after 8 days of care (if initial score >0) **Denominator**: Total patients x 100 **Exclusion**: **Performance standard**: 75%
Peruselli, 1997 30	Palliative care services must meet the physical, psychological, social and spiritual needs of patients Outcome	**Numerator**: Number of patients with score for communication professional to patient and family (STAS item) of 0-1 during final week of life **Denominator**: Total patients x 100 **Exclusion**: **Performance standard**: 75%
Yabroff, 2004 31	Percentage of patients within and among health facilities or systems with evidence that care plan was implemented by all providers consistent with goals of care Outcome	**Numerator**: **Denominator**: **Exclusion**: **Performance standard**:
Yabroff, 2004 32	Percentage of patients within and among health facilities or systems with evidence of care planning and provider-provider communication consistent with goals of care Process	**Numerator**: **Denominator**: **Exclusion**: **Performance standard**:
Mularski, 2006 33	Documentation that the goals of care and resuscitation status are communicated to the receiving team on transfer of the patient out of the ICU Process	**Numerator**: Total number of patients transferred out of the ICU with documentation that the goals of care and resuscitation status were communicated to the receiving team **Denominator**: Total number of patients transferred out of the ICU alive to another service in the hospital or other care facility **Exclusion**: Patients who die in the ICU and patients discharged to home from the ICU without home care services **Performance standard**:
Mularski, 2006 34	Documentation of the goals of care, in the patient chart, within 72 hours Process	**Numerator**: Total number of patients in the ICU for >72 hours with documentation of the goals of care **Denominator**: Total number of patients in the ICU for >72 hours **Exclusion**: **Performance standard**:
Mularski, 2006 35	Documentation of a policy that allows for continuity of nursing care for patients with multiple-day stay in the ICU for patients and family members Structure	**Numerator**: Presence of a policy in the ICU that supports arranging continuity of nurses for patients who spend >1 day in the ICU **Denominator**: ICU **Exclusion**: **Performance standard**:

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Reference/Year	Description + Type Indicator	Numerator/Denominator/Exclusion/ Performance Standard
Lorenz, 2007 36	Advance directive and surrogate continuity **IF** a VE has an advance directive in the outpatient, inpatient, or nursing home medical record, or the patient reports the existence of an advance directive in an interview, and the patient receives care in a second venue, **THEN** the advance directive should be present in the medical record at the second venue, or documentation should acknowledge its existence and its contents, **BECAUSE** an advance directive can guide care only if its existence is recognized and its content is known Process	**Numerator**: **Denominator**: **Exclusion**: **Performance standard**:
Twaddle, 2007 37	Documentation of patient status Percentage of all patients with documentation of prognosis, psychosocial symptoms, functional status, and overall symptom distress within 48 hours of admission Process	**Numerator**: **Denominator**: **Exclusion**: **Performance standard**: 90%
Lorenz, 2007 38	Comprehensive palliative assessement **IF** a VE dies an expected death with metastatic cancer, oxygen-dependent pulmonary disease, New York Heart Association (NYHA) Class III to IV congestive heart failure (CHF). end-stage (stage IV) renal disease, or dementia, **THEN** the chart should document pain and other symptoms, spiritual and existential concerns, caregiver burdens and needs for practical assistance, and advance care planning (ACP) within 6 months before death, **BECAUSE** these concerns are known to be important to patients with advanced illnesses as part of their late-life care Process	**Numerator**: **Denominator**: **Exclusion**: **Performance standard**:
Yabroff, 2004 39	Percentage of patients within and among health facilities or systems where evidence exists to confirm patient/family/caregiver participation in the discussion and development of their treatment goals Process	**Numerator**: **Denominator**: **Exclusion**: **Performance standard**:
National Hospice and Palliative Care Organization (NHPCO), 2006 Brown University, 2006 40	Provide coordination of care (Family evaluation of hospice care) Questions: F1: How often did someone from the hospice team give confusing or contradictory information about the patient's medical treatment? F2: While under the care of hospice, was there always one nurse who was identified as being in charge of the patient's overall care? F3: Was there any problem with hospice doctors or nurses not knowing enough about the patient's medical history to provide the best possible care? Process	**Numerator**: Sum of 1 response to survey instrument by family member of deceased patient **Denominator**: Number of items (=3) **Exclusion**: Patients who are not enrolled in a hospice program or have disenrolled from a hospice program. Live discharged are excluded **Performance standard**:
Twaddle, 2007 41	Patient/family meeting Percentage of all cases with documentation that a patient/family meeting (i.e., meeting between patient/family and members of the health care team to discuss the patient's treatment preferences or the plans for discharge disposition) occurred during the first week of the hospital stay Process	**Numerator**: **Denominator**: **Exclusion**: **Performance standard**: 90%

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Reference/Year	Description + Type Indicator	Numerator/Denominator/Exclusion/ Performance Standard
Peruselli, 1997 42	Satisfaction for patients and families is crucial to palliative care services, which considers clients to be their central focus Outcome	**Numerator**: Number of responses to questionnaire items answered "excellent" by both patient and family **Denominator**: Total number of responses x 100 **Exclusion**: **Performance standard**: 75%
Twaddle, 2007 43	Documentation of discharge plan Percentage of all patients with documentation of discharge plan (i.e., early documentation of statements such as "likely to require health services at discharge" or "not expected to survive this admission") within 4 days of admission Process	**Numerator**: **Denominator**: **Exclusion**: **Performance standard**: 90%
Twaddle, 2007 44	Discharge planner arranged services required for discharge Percentage of all cases with documentation that a discharge planner or other hospital personnel arranged any home services necessary Process	**Numerator**: **Denominator**: **Exclusion**: **Performance standard**: 90%
Domain 2: Physical aspects of care (44x)		
Keay, 1994 45	If patient had pain, this is followed to assess results of intervention *and* pain is reduced Process/outcome	**Numerator**: **Denominator**: **Exclusion**: Intractable pain even after consultation **Performance standard**: $>$ 80%
Keay, 1994 46	If terminally ill patient is reported to be in pain, this is addressed by the physician and active attempts are made to reduce pain Process	**Numerator**: **Denominator**: **Exclusion**: Minor pain symptoms in cognitively intact patients **Performance standard**: 100%
Nelson, 2006 Mularski, 2006 47	Regular pain assessment: percentage of 4 hour intervals with documentation of pain assessment Process	**Numerator**: Number of 4-hour intervals for which pain was assessed and documented using an appropriate rating scale **Denominator**: Total number of 4-hour intervals on days 0 and 1 (for patients admitted to ICU within the last 24 hours) **Exclusion**: Time spent off the unit and no longer in the care of the ICU nurse (e.g., in the operating room); potential **Exclusion**s: comatose patients patients (e.g., Glasgow Coma Score of 2 T or 3) **Performance standard**:
Nelson, 2006 Mularski, 2006 48	Optimal pain management: percentage of 4 hour intervals with documented pain score $\leq$ 3 on 1-10 scale Outcome	**Numerator**: Number of 4-hour intervals for which pain score was $\leq$ 3 on 1-10 scale (or equivalent) **Denominator**: Total number of 4-hour intervals on days 0 and 1 (for patients admitted to ICU within the last 24 hours) **Exclusion**: Time spent off the unit and no longer in the care of the ICU nurse (e.g., in the operating room) **Performance standard**:
Lorenz, 2007 49	Management of emergent pain and obstruction **IF** a VE who was conscious during the last 7 days of life died an expected death, **THEN** the medical record should contain documentation about presence or absence of pain during the last 7 days of life, **BECAUSE** pain is common at the end of life and can be effectively treated Process	**Numerator**: **Denominator**: **Exclusion**: **Performance standard**:

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Reference/Year	Description + Type Indicator	Numerator/Denominator/Exclusion/ Performance Standard
Peruselli, 1997 50	Palliative care services must meet the physical, psychological, social and spiritual needs of patients Outcome	**Numerator**: Number of patients with score for pain control (STAS item) dropped after 8 days of care (if initial score >0) **Denominator**: Total patients × 100 **Exclusion**: **Performance standard**: 75%
Peruselli, 1997 51	Palliative care services must meet the physical, psychological, social and spiritual needs of patients Outcome	**Numerator**: Number of patients with score for pain control (STAS item) of 0-1 during final week of life **Denominator**: Total patients × 100 **Exclusion**: **Performance standard**: 75%
Peruselli, 1997 52	Palliative care services must meet the physical, psychological, social and spiritual needs of patients Outcome	**Numerator**: Number of patients with global scores for pain (TIQ scale) dropped after 8 days of care (if initial score on the same scale >25) **Denominator**: Total patients × 100 **Exclusion**: **Performance standard**: 75%
Peruselli, 1997 53	Palliative care services must meet the physical, psychological, social and spiritual needs of patients Outcome	**Numerator**: Number of patients with global scores for pain (TIQ scale) not increased over initial score during final week of care (if initial score on the same scale >25) **Denominator**: Total patients × 100 **Exclusion**: **Performance standard**: 75%
National Hospice and Palliative Care Organization (NHPCO), 2006 Brown University, 2006 54	Family evaluation of hospice care: Symptom management Questions: B1: While under the care of hospice, did the patient have pain or take medicine for pain? B2: How much medicine did the patient receive for his/her pain? Process	**Numerator**: Those who received too much or too little help concerning pain **Denominator**: Those who experience pain **Exclusion**: Patients who are not enrolled in a hospice program or have disenrolled from a hospice program. Live discharged are excluded **Performance standard**:
National Hospice and Palliative Care Organization (NHPCO), 2006 55	Comfortable dying Outcome	**Numerator**: Patients whose pain was brought under control within 48 hours of admission to hospice **Denominator**: Patients who were uncomfortable because of pain on admission to hospice **Exclusion**: **Performance standard**:
Twaddle, 2007 56	Pain assessment Percentage of all patients with documentation of pain assessment within 48 hours of admission Process	**Numerator**: **Denominator**: **Exclusion**: **Performance standard**: 90%
Twaddle, 2007 57	Use of a quantitative pain rating scale Percentage of patients with pain evaluated according to a numeric or other validated pain scale Process	**Numerator**: **Denominator**: Patients reporting pain within 48 hours of admission **Exclusion**: **Performance standard**: 90%
Twaddle, 2007 58	Reduction or relief of pain Percentage of patients with pain relieved or reduced (i.e., pain score of 3 or less) within 48 hours of admission Outcome	**Numerator**: **Denominator**: Patients reporting pain **Exclusion**: **Performance standard**: 90%

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Reference/Year	Description + Type Indicator	Numerator/Denominator/Exclusion/ Performance Standard
Lorenz, 2007 59	Management of emergent pain and obstruction **IF** a VE with end-stage metastatic cancer is treated with opiates for pain, **THEN** the medical record should document a plan for management of worsening or emergent pain, **BECAUSE** increasing symptom burden is common with the progression of cancer and significantly impairs patient quality of life Process	**Numerator**: **Denominator**: **Exclusion**: **Performance standard**:
Lorenz, 2007 60	Management of emergent pain and obstruction **IF** a VE with end-stage metastatic cancer has obstructive gastrointestinal symptoms, **THEN** the medical record should document a plan for management of worsening or emergent nausea and vomiting, **BECAUSE** increasing symptom burden is common with these conditions and significantly impairs patient quality of life Process	**Numerator**: **Denominator**: **Exclusion**: **Performance standard**:
Mularski, 2006 61	Documentation of respiratory distress assessment (for nonventilated patient) or patient-ventilator dyssynchrony (for ventilated patients) every 8 hours Process	**Numerator**: Total number of 8-hour periods during the proportion of the 24-hour day that a patient is in the ICU or under care of the ICU nurse for which dyspnea/dyssynchrony is assessed and recorded using a quantitative rating scale **Denominator**: Total number of 8-hour periods that a patient is in the ICU during the proportion of the 24-hour day that a patient is in the ICU or under care of the ICU nurse **Exclusion**: Time spent off the unit and no longer in the care of the ICU nurse (e.g., in the operating room) **Performance standard**:
Mularski, 2006 62	Treatment of or management plan for respiratory distress (for non-ventilated patients) or patient-ventilator dyssynchrony (for ventilated patients) that is assessed as >3 on a 1-10 scale or greater than mild on other scales with reassessment after treatment Process/outcome	**Numerator**: Total number of 8-hour periods during the proportion of the 24-hour day that a patient is in the ICU or under care of the ICU nurse for which respiratory distress/ dyssynchony is assessed as >3 (or greater than mild) and there is a documented treatment/ management plan provided and documented reassessment within 2 hours after treatment/ management plan **Denominator**: Total number of 8-hour periods during the proportion of the 24-hour day that a patient is in the ICU or under care of the ICU nurse for which respiratory distress/ dyssynchony is assessed as >3 (or greater than mild) **Exclusion**: Time spent off the unit and no longer in the care of the ICU nurse (e.g., in the operating room) **Performance standard**:
Mularski, 2006 63	Documentation of opioids, benzodiazepines, or similar agents prescribed to manage distress or dyspnea for noncomatose patients undergoing terminal withdrawal of mechanical ventilation Process	**Numerator**: Total number of noncomatose patients for whom mechanical ventilation is withdrawn in anticipation of death who have an order written for opiates or benzodizepines as scheduled or as needed **Denominator**: Total number of noncomatose patients for whom mechanical ventilation is withdrawn in anticipation of death **Exclusion**: Comatose patients (e.g., Glasgow Coma Score of 2T or 3) **Performance standard**:

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Reference/Year	Description + Type Indicator	Numerator/Denominator/Exclusion/ Performance Standard
Keay, 1994 64	Dyspnea, if present, is addressed *and* attempts are made to minimize dyspnea Process	**Numerator**: **Denominator**: **Exclusion**: Physicians not made aware of dyspnea **Performance standard**: 100%
Lorenz, 2007 65	Mechanical ventilator withdrawal **IF** a noncomatose VE is not expected to survive, and a mechanical ventilator is withdrawn or withheld, **THEN** the chart should document whether the patient has dyspnea, and the patient should receive (or have orders available for) an opiate, benzodiazepine, or barbiturate infusion, **BECAUSE** dyspnea can be controlled in the setting of comfort care when mechanical ventilation is withdrawn or withheld Process	**Numerator**: **Denominator**: **Exclusion**: **Performance standard**:
Lorenz, 2007 66	Management of emergent dyspnea **IF** a VE who has dyspnea in the last 7 days of life died an expected death, **THEN** the chart should document dyspnea care and follow-up, **BECAUSE** dyspnea can be effectively treated with oxygen and pharmacological agents Process	**Numerator**: **Denominator**: **Exclusion**: **Performance standard**:
Peruselli, 1997 67	Palliative care services must meet the physical, psychological, social and spiritual needs of patients Outcome	**Numerator**: Number of patients with global scores for breathing difficulties (TIQ scale) dropped after 8 days of care (if initial score on the same scale >25) **Denominator**: Total patients x 100 **Exclusion**: **Performance standard**: 75%
Peruselli, 1997 68	Palliative care services must meet the physical, psychological, social and spiritual needs of patients Outcome	**Numerator**: Number of patients with global scores for breathing difficulties (TIQ scale) not increased over initial score during final week of care (if initial score on the same scale >25) **Denominator**: Total patients x 100 **Exclusion**: **Performance standard**: 75%
National Hospice and Palliative Care Organization (NHPCO), 2006 Brown University, 2006 69	Family evaluation of hospice care: Symptom management Questions: B5: While under the care of hospice, did the patient have trouble breathing? B6: How much help in dealing with his/her breathing did the patient receive while under the care of hospice? Outcome	**Numerator**: Those who received too much or too little help concerning shortness of breath **Denominator**: Those who experience shortness of breath **Exclusion**: Patients who are not enrolled in a hospice program or have disenrolled from a hospice program. Live discharged are excluded **Exclusion**: **Performance standard**:
Twaddle, 2007 70	Dyspnea assessment Percentage of all patients with documentation of dyspnea assessment within 48 hours of admission Process	**Numerator**: **Denominator**: **Exclusion**: **Performance standard**: 90%
Twaddle, 2007 71	Reduction or relief of dyspnea Percentage of patients with dyspnea relieved or reduced (i.e., score of 3 or less on a 10-point scale) within 48 hours of admission Outcome	**Numerator**: **Denominator**: Patients reporting dyspnea **Exclusion**: **Performance standard**: 90%

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Reference/Year	Description + Type Indicator	Numerator/Denominator/Exclusion/ Performance Standard
Lorenz, 2007 72	Dyspnea assessment **IF** a VE is diagnosed with lung cancer, or cancer metastatic to lung, NYHA Class III to IV CHF, or oxygen-dependent pulmonary disease, **THEN** a self-reported assessment of dyspnea should be documented in the outpatient chart, **BECAUSE** dyspnea is common in these conditions, and there are effective treatments for addressing dyspnea Process	**Numerator**: **Denominator**: **Exclusion**: **Performance standard**:
Lorenz, 2007 73	Treatment of dyspnea **IF** a VE with meastatic cancer or oxygen-dependent pulmonary disease has dyspnea refractory to nonopiate medications, **THEN** opiate medications should be offered, **BECAUSE** opiates effectively treat dyspnea from advanced cancer and chronic obstructive pulmonary disease Process	**Numerator**: **Denominator**: **Exclusion**: **Performance standard**:
Lorenz, 2007 74	Management of emergent dyspnea **IF** a VE is in hospice or has a preference for no hospitalization and is living with oxygen-dependent pulmonary disease, lung cancer, or NYHA Class III to IV CHF, **THEN** the medical record should document a plan for management of worsening or emergent dyspnea, **BECAUSE** increasing symptom burden is common with the progression of these illnesses and significantly impairs patient quality of life Process	**Numerator**: **Denominator**: **Exclusion**: **Performance standard**:
Peruselli, 1997 75	Palliative care services must meet the physical, psychological, social and spiritual needs of patients Outcome	**Numerator**: Number of patients with global scores for fatigue (TIQ scale) dropped after 8 days of care (if initial score on the same scale > 25) **Denominator**: Total patients x 100 **Exclusion**: **Performance standard**: 75%
Peruselli, 1997 76	Palliative care services must meet the physical, psychological, social and spiritual needs of patients Outcome	**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) **Denominator**: Total patients x 100 **Exclusion**: **Performance standard**: 75%
Peruselli, 1997 77	Palliative care services must meet the physical, psychological, social and spiritual needs of patients Outcome	**Numerator**: Number of patients with global scores for constipation (TIQ scale) dropped after 8 days of care (if initial score on the same scale >25) **Denominator**: Total patients x 100 **Exclusion**: **Performance standard**: 75%
Peruselli, 1997 78	Palliative care services must meet the physical, psychological, social and spiritual needs of patients Outcome	**Numerator**: Number of patients with global scores for constipation (TIQ scale) not increased over initial score during final week of care (if initial score on the same scale >25) **Denominator**: Total patients x 100 **Exclusion**: **Performance standard**: 75%

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Reference/Year	Description + Type Indicator	Numerator/Denominator/Exclusion/ Performance Standard
Peruselli, 1997 79	Palliative care services must meet the physical, psychological, social and spiritual needs of patients Outcome	**Numerator**: Number of patients with global scores for gastrointestinal symptoms (TIQ scale) dropped after 8 days of care (if initial score on the same scale >25) **Denominator**: Total patients × 100 **Exclusion**: **Performance standard**: 75%
Peruselli, 1997 80	Palliative care services must meet the physical, psychological, social and spiritual needs of patients Outcome	**Numerator**: Number of patients with global scores for gastrointestinal symptoms (TIQ scale) not increased over initial score during final week of care (if initial score on the same scale >25) **Denominator**: Total patients × 100 **Exclusion**: **Performance standard**: 75%
Twaddle, 2007 81	Bowel regimen ordered in conjunction with opioid administration Percentage of patients receiving opioids who had an order for a bowel regimen written within 24 hours of order for the opioid Process	**Numerator**: **Denominator**: **Exclusion**: **Performance standard**: 90%
Yabroff, 2004 82	Percentage of patients within and among health facilities or systems with evidence that symptom relief was achieved and unmet needs were met with appropriate response or resolved Outcome	**Numerator**: **Denominator**: **Exclusion**: **Performance standard**:
Peruselli, 1997 83	Palliative care services must meet the physical, psychological, social and spiritual needs of patients Outcome	**Numerator**: Number of patients with score for symptom control other than pain (STAS item) dropped after 8 days of care (if initial score >0) **Denominator**: Total patients × 100 **Exclusion**: **Performance standard**: 75%
Peruselli, 1997 84	Palliative care services must meet the physical, psychological, social and spiritual needs of patients Outcome	**Numerator**: Number of patients with score for symptom control other than pain (STAS item) of 0-1 during final week of life **Denominator**: Total patients × 100 **Exclusion**: **Performance standard**: 75%
Peruselli, 1997 85	Palliative care services must meet the physical, psychological, social and spiritual needs of patients Outcome	**Numerator**: Number of patients with global scores for physical symptoms (=comprising TIQ scales: fatigue, gastrointestinal symptoms and global health status) dropped after 8 days of care (if initial score on the same scale >25) **Denominator**: Total patients × 100 **Exclusion**: **Performance standard**: 75%
Peruselli, 1997 86	Palliative care services must meet the physical, psychological, social and spiritual needs of patients Outcome	**Numerator**: Number of patients with global scores for physical symptoms (=comprising TIQ scales: fatigue, gastrointestinal symptoms and global health status) not increased over initial score during final week of care (if initial score on the same scale >25) **Denominator**: Total patients × 100 **Exclusion**: **Performance standard**: 75%
Peruselli, 1997 87	Palliative care services must meet the physical, psychological, social and spiritual needs of patients Outcome	**Numerator**: Number of patients with global scores for global health status (TIQ scale) dropped after 8 days of care (if initial score on the same scale >25) **Denominator**: Total patients × 100 **Exclusion**: **Performance standard**: 75%

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Reference/Year	Description + Type Indicator	Numerator/Denominator/Exclusion/ Performance Standard
Peruselli, 1997 88	Palliative care services must meet the physical, psychological, social and spiritual needs of patients Outcome	**Numerator**: Number of patients with global scores for global health status (TIQ scale) not increased over initial score during final week of care (if initial score on the same scale >25) **Denominator**: Total patients × 100 **Exclusion**: **Performance standard**: 75%
Domain 3: Psychological and psychiatric aspects of care (20x)		
Peruselli, 1997 89	Palliative care services must meet the physical, psychological, social and spiritual needs of patients Outcome	**Numerator**: Number of patients with global scores for functional impairment (TIQ scale) dropped after 8 days of care (if initial score on the same scale >25) **Denominator**: Total patients × 100 **Exclusion**: **Performance standard**: 75%
Peruselli, 1997 90	Palliative care services must meet the physical, psychological, social and spiritual needs of patients Outcome	**Numerator**: Number of patients with global scores for functional impairment (TIQ scale) not increased over initial score during final week of care (if initial score on the same scale >25) **Denominator**: Total patients × 100 **Exclusion**: **Performance standard**: 75%
Saliba, 2006 91	**IF** a nursing home resident was conscious during any of the last 7 days of life and died an expected death, **THEN** their should be medical record documentation about emotional distress (presence, absence, or inability to assess) in the last 7 days of life Process	**Numerator**: **Denominator**: **Exclusion**: **Performance standard**:
Peruselli, 1997 92	Palliative care services must meet the physical, psychological, social and spiritual needs of patients Outcome	**Numerator**: Number of patients with score for patient anxiety (STAS item) dropped after 8 days of care (if initial score >0) **Denominator**: Total patients × 100 **Exclusion**: **Performance standard**: 75%
Peruselli, 1997 93	Palliative care services must meet the physical, psychological, social and spiritual needs of patients Outcome	**Numerator**: Number of patients with score for patient anxiety (STAS item) of 0-1 during final week of life **Denominator**: Total patients × 100 **Exclusion**: **Performance standard**: 75%
Peruselli, 1997 94	Palliative care services must meet the physical, psychological, social and spiritual needs of patients Outcome	**Numerator**: Number of patients with score for family anxiety (STAS item) dropped after 8 days of care (if initial score >0) **Denominator**: Total patients × 100 **Exclusion**: **Performance standard**: 75%
Peruselli, 1997 95	Palliative care services must meet the physical, psychological, social and spiritual needs of patients Outcome	**Numerator**: Number of patients with score for family anxiety (STAS item) of 0-1 during final week of life **Denominator**: Total patients × 100 **Exclusion**: **Performance standard**: 75%
National Hospice and Palliative Care Organization (NHPCO), 2006 Brown University, 2006 96	Family evaluation of hospice care: Symptom management Questions: B9: While under the care of hospice, did the patient have any feelings of anxiety or sadness? B10: How much help in dealing with these feelings did the patient receive? Outcome	**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 **Performance standard**:

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Reference/Year	Description + Type Indicator	Numerator/Denominator/Exclusion/ Performance Standard
Peruselli, 1997 97	Palliative care services must meet the physical, psychological, social and spiritual needs of patients Outcome	**Numerator**: Number of patients with global scores for cognitive status (TIQ scale) dropped after 8 days of care (if initial score on the same scale >25) **Denominator**: Total patients × 100 **Exclusion**: **Performance standard**: 75%
Peruselli, 1997 98	Palliative care services must meet the physical, psychological, social and spiritual needs of patients Outcome	**Numerator**: Number of patients with global scores for cognitive status (TIQ scale) not increased over initial score during final week of care (if initial score on the same scale >25) **Denominator**: Total patients × 100 **Exclusion**: **Performance standard**: 75%
National Hospice and Palliative Care Organization (NHPCO), 2006 Brown University, 2006 99	Attend to family needs (Family evaluation of hospice care) Questions: E2: Did you have as much contact about your religious or spiritual beliefs as you wanted? E3: How much emotional support did the hospice team provide to you prior to the patient's death? E4: How much emotional support did the hospice team provide to you after the patient's death? Outcome	**Numerator**: Sum of 1 response to survey instrument by family member of deceased patient **Denominator**: Number of items (=3) **Exclusion**: Patients who are not enrolled in a hospice program or have disenrolled from a hospice program. Live discharged are excluded **Performance standard**:
Yabroff, 2004 100	Percentage of patients within and among health facilities or systems with evidence for ongoing quality of life assessment reflected in the treatment plan Process	**Numerator**: **Denominator**: **Exclusion**: **Performance standard**:
Peruselli, 1997 101	Palliative care services must meet the physical, psychological, social and spiritual needs of patients Outcome	**Numerator**: Number of patients with global scores for emotional status (TIQ scale) dropped after 8 days of care (if initial score on the same scale >25) **Denominator**: Total patients × 100 **Exclusion**: **Performance standard**: 75%
Peruselli, 1997 102	Palliative care services must meet the physical, psychological, social and spiritual needs of patients Outcome	**Numerator**: Number of patients with global scores for emotional status (TIQ scale) not increased over initial score during final week of care (if initial score on the same scale >25) **Denominator**: Total patients × 100 **Exclusion**: **Performance standard**: 75%
Peruselli, 1997 103	Palliative care services must meet the physical, psychological, social and spiritual needs of patients Outcome	**Numerator**: Number of patients with global scores for therapy impact index (=comprising functional impairment, emotional status, cognitive status, social interaction TIQ scales) dropped after 8 days of care (if initial score on the same scale >25) **Denominator**: Total patients × 100 **Exclusion**: **Performance standard**: 75%
Peruselli, 1997 104	Palliative care services must meet the physical, psychological, social and spiritual needs of patients Outcome	**Numerator**: Number of patients with global scores for therapy impact index (=comprising functional impairment, emotional status, cognitive status, social interaction TIQ scales) not increased over initial score during final week of care (if initial score on the same scale >25) **Denominator**: Total patients × 100 **Exclusion**: **Performance standard**: 75%

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Reference/Year	Description + Type Indicator	Numerator/Denominator/Exclusion/ Performance Standard
Peruselli, 1997 105	Palliative care services must meet the physical, psychological, social and spiritual needs of patients Outcome	**Numerator**: Number of patients with score for communication between patient and family (STAS item) dropped after 8 days of care (if initial score >0) **Denominator**: Total patients × 100 **Exclusion**: **Performance standard**: 75%
Peruselli, 1997 106	Palliative care services must meet the physical, psychological, social and spiritual needs of patients Outcome	**Numerator**: Number of patients with score for communication between patient and family (STAS item) of 0-1 during final week of life **Denominator**: Total patients × 100 **Exclusion**: **Performance standard**: 75%
Twaddle, 2007 107	Psychosocial assessment Al patients were expected to have a psychosocial assessment (i.e., a formal psychosocial assessment conducted by a psychologist, social worker, psychiatrist or other expert) completed within 1 year prior or 4 days after admission Process	**Numerator**: **Denominator**: **Exclusion**: **Performance standard**: 90%
Keay, 1994 108	Psychological or social support is documented in the patient's medical record Process	**Numerator**: **Denominator**: **Exclusion**: Patient death within a few hours of being declared terminally ill; patient cognitively impaired *and* family or friends are not reasonably available **Performance standard**: > 80%
Domain 4: Social aspects of care (6x)		
Mularski, 2006 109	Documentation of offering of psychosocial support within the first 72 hours of admission to the ICU Process	**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 2T or 3) with no family member of friend identified **Performance standard**:
Nelson, 2006 110	Social work support: percentage of patients with documentation that social work support was offered to the patient/family Process	**Numerator**: Number of patients with documentation that social work support was offered to the patient/family **Denominator**: Total number of patients with ICU length of stay ≥ 3 days **Exclusion**: **Performance standard**:
Peruselli, 1997 111	Support provided to patient and family also includes home visits by voluntary workers Process	**Numerator**: Number of patients who have had home visits by voluntary workers **Denominator**: Population served × 100 **Exclusion**: **Performance standard**: 30%
Peruselli, 1997 112	Palliative care services must meet the physical, psychological, social and spiritual needs of patients Outcome	**Numerator**: Number of patients with global scores for social interaction (TIQ scale) dropped after 8 days of care (if initial score on the same scale >25) **Denominator**: Total patients × 100 **Exclusion**: **Performance standard**: 75%
Peruselli, 1997 113	Palliative care services must meet the physical, psychological, social and spiritual needs of patients Outcome	**Numerator**: Number of patients with global scores for social interaction (TIQ scale) not increased over initial score during final week of care (if initial score on the same scale >25) **Denominator**: Total patients × 100 **Exclusion**: **Performance standard**: 75%

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Reference/Year	Description + Type Indicator	Numerator/Denominator/Exclusion/ Performance Standard
Lorenz, 2007 114	Caregiver stress **IF** a VE is a caregiver for a spouse, significant other, or dependent who is terminally ill or has very limited function, **THEN** the VE should be assessed for caregiver financial, physical, and emotional stress, **BECAUSE** caregiver burden is substantial in these situations and associated with poor outcomes Process	**Numerator**: **Denominator**: **Exclusion**: **Performance standard**:
Domain 5: Spiritual, religious and existential aspects of care (1x)		
Nelson, 2006, Mularski, 2006 115	Spiritual support: percentage of patients with documentation that spiritual support was offered to the patient/family Process	**Numerator**: Number of patients with documentation that spiritual support was offered to the patient/family **Denominator**: Total number of patients with ICU length of stay $\geq$ 3 days **Exclusion**: Patients with no family members visiting the patient during the ICU stay **Performance standard**:
Domain 6: Cultural aspects of care		
Domain 7: Care for the imminently dying patient (11x)		
Earle, 2006 116	Proportion receiving chemotherapy in the last 14 days of life Process	**Numerator**: Patients who died from cancer and received chemotherapy in the last 14 days of life **Denominator**: Patients who died from cancer **Exclusion**: **Performance standard**: $<$ 10%
Earle, 2006 117	Proportion with more than one emergency room (ER) visit in the last 30 days of life Process	**Numerator**: Patients who died from cancer and had >1 ER visit in the last 30 days of life **Denominator**: Patients who died from cancer **Exclusion**: **Performance standard**: $<$ 4%
Earle, 2006 118	Proportion with more than one hospitalization in the last 30 days of life Process	**Numerator**: Patients who died from cancer and had >1 hospitalization in the last 30 days of life **Denominator**: Patients who died from cancer **Exclusion**: **Performance standard**: $<$ 4%
Earle, 2006 119	Proportion admitted to the ICU in the last 30 days of life Process	**Numerator**: Patients who died from cancer and were admitted to the ICU in the last 30 days of life **Denominator**: Patients who died from cancer **Exclusion**: **Performance standard**: $<$ 4%
Mularski, 2006 120	Documentation of a protocol for provision of analgesia and sedation during terminal withdrawal of mechanical ventilation Structure	**Numerator**: Presence of a protocol that can be applied in settings of terminal withdrawal of mechanical ventilation **Denominator**: ICU **Exclusion**: **Performance standard**:
Peruselli, 1997 121	Home palliative care services must ensure continuous care for the patient until the final moments of life, and for the family after the patient's death by helping to deal with the mourning process Process	**Numerator**: Number of families who have received home visits on the day of patient's death **Denominator**: Population served × 100 **Exclusion**: **Performance standard**: 90%
Peruselli, 1997 122	Home palliative care services must ensure continuous care for the patient until the final moments of life, and for the family after the patient's death by helping to deal with the mourning process Process	**Numerator**: Number of families who have received home visits in the days following patient's death to provide support during the mourning process **Denominator**: Population served × 100 **Exclusion**: **Performance standard**: 90%

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Reference/Year	Description + Type Indicator	Numerator/Denominator/Exclusion/ Performance Standard
Keay,1994 123	Follow-up bereavement counseling is offered by the physician Process	**Numerator**: **Denominator**: **Exclusion**: **Performance standard**:
National Hospice and Palliative Care Organization (NHPCO), 2006 Brown University, 2006 124	Inform and communicate about patient (Family evaluation of hospice care) Questions: D5: How often did the hospice team keep you or other family members informed about the patient's condition? D7: Would you have wanted more information about what to expect while the patient was dying? Process	**Numerator**: Sum of 1 response to survey instrument by family member of deceased patient **Denominator**: Number of items (=2) **Exclusion**: Patients who are not enrolled in a hospice program or have disenrolled from a hospice program. Live discharged are excluded **Performance standard**:
National Hospice and Palliative Care Organisation (NHPCO), 2006 Brown University, 2006 125	Provide information about symptoms (Family evaluation of hospice care) Questions: B4: Did you want more information than you got about the medicines used to manage the patient's pain? B8: Did you want more information than you got about what was being done for the patient's trouble with breathing? Process	**Numerator**: Sum of 1 response to survey instrument by family member of deceased patient **Denominator**: Number of items (=2) **Exclusion**: Patients who are not enrolled in a hospice program or have disenrolled from a hospice program. Live discharged are excluded **Performance standard**:
Lorenz, 2007 126	Bereavement **IF** a VE's spouse or significant other dies, **THEN** the VE should be assessed for depression or thoughts of suicidality within 6 months, **BECAUSE** bereaved persons are at high risk of poor outcomes Process	**Numerator**: **Denominator**: **Exclusion**: **Performance standard**:
Domain 8: Ethical and legal aspects of care (16x)		
Keay, 1994 127	Interventions not wanted by the patient are not performed Process	**Numerator**: **Denominator**: **Exclusion**: Conflicting patient directives **Performance standard**: > 80%
Lorenz, 2007 128	Decisions about life-sustaining treatment **IF** a VE has documented treatment preferences to withhold or withdraw life-sustaining treatment (e.g., DNR order, no tube feeding, no hospital transfer), **THEN** these treatment preferences should be followed, **BECAUSE** medical care should aim to be consistent with a patient's preferences Process	**Numerator**: **Denominator**: **Exclusion**: **Performance standard**:
Mularski, 2006 129	Assessment within 24 hours of admission of the patient's capacity to make decisions Process	**Numerator**: Total number of patients in the ICU with documentation of decisional capacity made within 24 hours of admission **Denominator**: Total number of patients in the ICU for >24 hours **Exclusion**: **Performance standard**:
Nelson, 2006, Mularski, 2006 130	Medical decision maker: Percentage of patients with documentation of status of identification of health care proxy (or other appropriate surrogate) Process	**Numerator**: Number of patients with documentation of status of identification of health care proxy (or other appropriate surrogate) **Denominator**: Total number of patients admitted to the ICU within the last 24 hours **Exclusion**: **Performance standard**:

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Reference/Year	**Description + Type Indicator**	**Numerator/Denominator/Exclusion/ Performance Standard**
Nelson, 2006, Mularski, 2006 131	Advance directive: percentage of patients with documentation of advance directive status on or before Day 1 of the ICU admission Process	**Numerator**: Number of patients who have documentation of advance directive status on or before day 1 of the ICU admission **Denominator**: Total number of patients with an ICU length of stay ≥ 5 days **Exclusion**: Patients discharged (or transferred out of the ICU) on or before Day 1 of ICU admission Patients expired on or before Day 1 of ICU admission Patients with decisional capacity **Performance standard**:
Nelson, 2006 132	Resuscitation status: percentage of patients with documentation of resuscitation status Process	**Numerator**: Number of patients with documentation of resuscitation status **Denominator**: Total number of patients admitted to the ICU within the last 24 hours **Exclusion**: **Performance standard**:
Keay, 1994 133	Documentation of patients wishes or advance directive is present Process	**Numerator**: **Denominator**: **Exclusion**: Patient was always incapacitated and without advance directive or legal proxy **Performance standard**: 100%
Lorenz, 2007 134	ACP documented **ALL** VEs should have in the outpatient chart patient's surrogate decision maker, or documentation of a discussion to identify or search for a surrogate decision maker, **BECAUSE**, advance directives and discussions about surrogate decisions makers facilitate identification of surrogate decision makers and decision making on behalf of a patient who has lost decision-making capacity Process	**Numerator**: **Denominator**: **Exclusion**: **Performance standard**:
Lorenz, 2007 135	Advance directive and surrogate continuity **IF** a VE is admitted to the hospital or nursing home, **THEN** within 48 hours of admission, the medical record should contain the patient's surrogate decision maker or documentation of a discussion to identify or search for surrogate decision maker, **BECAUSE** specification of a surrogate decision maker facilitates decision making for patients at risk of losing decision making capacity Process	**Numerator**: **Denominator**: **Exclusion**: **Performance standard**:
Lorenz, 2007 136	Care-preference documentation **IF** a VE with severe dementia is admitted to the hospital and survives 48 hours, **THEN** within 48 hours of admission, the medical record should document that the patient's preferences for care have been considered or an attempt was made to identify them, **BECAUSE** patient's values and preferences should guide life-sustaining care Process	**Numerator**: **Denominator**: **Exclusion**: **Performance standard**:
Lorenz, 2007 137	Care-preference documentation **IF** a VE is admitted to the ICU and survives 48 hours, **THEN** within 48 hours of ICU admission, the medical record should document that the patient's preferences for care have been considered or an attempt was made to identify them, **BECAUSE** patient's values and preferences should guide life-sustaining care Process	**Numerator**: **Denominator**: **Exclusion**: **Performance standard**:

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Reference/Year	**Description + Type Indicator**	**Numerator/Denominator/Exclusion/ Performance Standard**
Lorenz, 2007 138	Decisions about life-sustaining treatment **IF** a VE with decision-making capacity has orders in the hospital or nursing home to withhold or withdraw a life-sustaining treatment (e.g., DNR order), **THEN** the medical record should document patient participation in the decision or why the patient did not participate, **BECAUSE** the values of patients with decision-making capacity who wish to participate should guide important care decisions Process	**Numerator**: **Denominator**: **Exclusion**: **Performance standard**:
Lorenz, 2007 139	Mechanical ventilation preference **IF** a hospitalized VE requires mechanical ventilation for longer then 48 hours, **THEN** within 48 hours of the initiation of the mechanical ventilation, the medical record should document the goals of care and the patient's preference for mechanical ventilation or why this information is unavailable, **BECAUSE** mechanical ventilation should be performed only when it is consistent with a patient's goals, and early consideration of prognosis and preferences will guide care to be consistent with the patient's values Process	**Numerator**: **Denominator**: **Exclusion**: **Performance standard**:
Saliba, 2004 140	**ALL** residents, within 2 weeks of NH admission, should have physician notes or orders documenting a discussion or decision concerning all of the following: resuscitation status, hospital transfers, and advance directives, unless there is documentation that the resident is not capable of understanding and surrogate could not be located. This information should remain available in the chart throughout the resident's stay. Process	**Numerator**: **Denominator**: **Exclusion**: When there is documentation that the resident is not capable of understanding and surrogate could not be located **Performance standard**: 100%
Lorenz, 2007 141	Goals of care surrogate discussion **IF** a VE dies an expected death with metastatic cancer, oxygen-dependent pulmonary disease, New York Heart Association (NYHA) Class III to IV congestive heart failure (CHF). end-stage (stage IV) renal disease, or dementia, **THEN** the chart should document discussion of the medical condition and goals for treatment with a designated surrogate, the patient's preferences for not involving a designated surrogate in discussions, or a note that a surrogate decision maker is unavailable within 6 months before death, **BECAUSE** temporary decisional incapacity is common in these health states, and therefore, surrogates are at risk of being called upon to assist in achieving patient preferences, yet it is not routine for physicians to involve surrogates in care planning Process	**Numerator**: **Denominator**: **Exclusion**: **Performance standard**:

(*Continued*)

Continued

Reference/Year	Description + Type Indicator	Numerator/Denominator/Exclusion/ Performance Standard
Lorenz, 2007 142	Gastrostomy tube placement **IF** a VE with dementia has a gastrostomy or jejunum tube placed, **THEN** before placement, the medical record should document patient preferences concerning tube feeding; discussion of patient preferences or best interests if the patient is decisionally incapacitated and a surrogate decision maker is available; or use of a formal decision mechanism if the patient is decisionally incapacitated and a surrogate decision maker is not available, **BECAUSE** many patients would not want to receive tube feeding to maintain survival in a persistent severely compromised health state, and decisions are often made to place gastrostomy tubes when patients can no longer participate in decisions Process	**Numerator**: **Denominator**: **Exclusion**: **Performance standard**:

Appendix 3 References

Earle, 2006

- National Quality Forum. National voluntary consensus standards for symptom management and end-of-life care in cancer patients. Washington DC: National Quality Forum; 2006. Available from: http://www.qualityforum.org/pdf/cancer/txWEBSX-EOLReport-ALL.pdf
- Earle CC, Park ER, Lai B, et al. Identifying potential indicators of the quality of end-of-life cancer care from administrative data. J Clin Oncol 2003;21(6):1133−1138.
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- 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.

Subject quality indicator set: Palliative cancer care.
We only used the quality indicators that were accepted by the National Quality Forum, 2006.

Keay, 1994

- Keay TJ, Fredman L, Taler GA, Datta S, Leverson SA. Indicators of quality medical care for the terminally ill in nursing homes. J Am Geriatr Soc 1994;42(8):853−860.

Subject quality indicator set: Palliative nursing home care[28]
Not all proposed quality indicators in the publication met the inclusion criteria for a quality indicators.

Lorenz, 2007, Saliba, 2006

- Wenger NS, Rosenfeld K. Quality indicators for end-of-life care in vulnerable elders. Ann Intern Med 2001;135(8 Pt 2):677-852.
- Saliba D, Solomon D, Rubenstein L, et al. Feasibility of quality indicators for the management of geriatric syndromes in nursing home residents. J Am Med Dir Assoc 2004;5(5):310−319.
- 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):S318−326.

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Subject quality indicator set: Vulnerable elderly in end-of-life care.

We used the quality indicators described in the updated (2007) version of the ACOVE set. Saliba et al. used the ACOVE set of 2001 to test feasibility of the quality indicators for nursing home patients. Two indicators were not used in the 2007 version, and are separately included in this review.

Mularski, 2006, Nelson, 2006

- Mularski RA, Curtis JR, Billings JA, et al. Proposed quality measures for palliative care in the critically ill: a consensus from the Robert Wood Johnson Foundation Critical Care Workgroup. Crit Care Med 2006;34(11 Suppl):S404-411.
- Nelson JE, Mulkerin CM, Adams LL, Pronovost PJ. 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.
- Clarke EB, Curtis JR, Luce JM, et al. Robert Wood Johnson Foundation Critical Care End-of-Life Peer Workgroup Members. Quality indicators for end-of-life care in the intensive care unit. Crit Care Med 2003;31(9):2255-2262.

Subject quality indicator set: ICU end-of-life care.

Mularski and Nelson used the same preliminary set of quality indicators for the ICU described by Clarke et al. 2003, but selected different quality indicators. We selected the quality indicators that are described in both publications and the quality indicators that are only described by Mularski or Nelson.

National Hospice and Palliative Care Organization (NHPCO), 2006

- National Quality Forum. National voluntary consensus standards for symptom management and end-of-life care in cancer patients. Washington DC: National Quality Forum; 2006 Available from: http://www.qualityforum.org/pdf/cancer/txWEBSX-EOLReport-ALL.pdf.

Subject quality indicator set: Family evaluation of hospice care.

We only selected the quality indicators which are accepted by the National Quality Forum.

Peruselli, 1997

- Peruselli C, Marinari M, Brivio B, et al. Evaluating a home palliative care service: development of indicators for a continuous quality improvement program. J Palliat Care 1997;13(3):34-42.

Subject quality indicator set: Home palliative care.

Not all proposed quality indicators in the publication met the inclusion criteria for a quality indicator.

Twaddle, 2007

- Twaddle ML, Maxwell TL, Cassel JB, et al. Palliative care benchmarks from academic medical centers. J Palliat Med 2007;10(1):86-98.

Subject quality indicator set: Hospital-based palliative care.[30]

All proposed quality indicators are included in the review.

Yabroff, 2004

- Yabroff KR, Mandelblatt JS, Ingham J. The quality of medical care at the end-of-life in the USA: existing barriers and examples of process and outcome measures. Palliat Med 2004;18(3):202-216.

Subject quality indicator set: Palliative cancer care.

Not all proposed quality indicators in the publication met the inclusion criteria for a quality indicator.