Quality indicators for palliative and end of life care: a review of Swedish policy documents

Susanne Lind, Jan Adolfsson, Bertil Axelsson, Carl Johan Fürst

ABSTRACT
Background All patients with palliative and end of life care needs should be guaranteed equal and safe treatment and care, regardless of their disease or site of care. The inclusion of quality indicators in national guidelines and other guiding documents supports quality assurance and improvement in provision of care. The aim of this paper was to review existing quality indicators in national Swedish policy documents relevant to palliative and end of life care.

Methods We reviewed existing guidelines for diseases expected to require palliative care issued by the National Board of Health and Welfare, existing regional practice guidelines and the annual report of the Swedish Register of Palliative Care (SRPC) up until 2010.

Results We found 11 quality indicators pertinent to palliative and end of life care in the guidelines for cancer diseases and ‘The care and nursing of the elderly’. The indicators included assessment and treatment of pain, communication with the patient and the family, documentation in the patient record and registration in the SRPC. In the national guidelines for cardiology, pulmonary diseases, stroke, diabetes and dementia, there were no indicators relevant for palliative or end of life care.

Conclusions In the existing Swedish national guidelines for many different diseases, there is still a great need to define clinically relevant and feasible outcome measures of quality of palliative and end of life care.

INTRODUCTION
All patients with palliative care needs should be guaranteed equal and safe treatment and care, regardless of their disease or site of care. This accords with the general aim of Swedish law, as laid down by a government commission, and it is stipulated as a basic human right. Work began on national clinical practice guidelines for palliative care in Sweden in 2009, with the goal of providing a commonly agreed upon knowledge base, and the first official version was published in March 2012. Quality indicators (QIs) are increasingly used to assess the quality of palliative care. Indicators and their measurement are not always well defined and vary on disease and care contexts. We conducted a review of existing QIs in national Swedish policy documents relevant to palliative care and end of life care.

How does the Swedish health care system define ‘quality’?
The word ‘quality’ describes a property but the meaning of this word has expanded in recent years such that ‘quality’ now refers to the ability of an object or a service to satisfy the needs and expectations of the customer, from various perspectives. The National Board of Health and Welfare (NBHW) defines ‘quality’ as ‘the degree to which a medical service satisfies the requirements placed on it’. The concept of ‘good care’ was launched in association with the publication of these regulations and general guidelines. Six quality domains were described as important and require health services and medical care to be knowledge based and appropriate, safe, patient focused, efficient, equitable and timely (box 1). The concept of ‘good care’ also requires palliative care to be provided throughout the healthcare system.

How is quality measured in the Swedish health care system?
A QI structures the work of quality assurance. The NBHW and the Swedish Association of Local Authorities and Regions use the following definition: ‘A quality indicator is a measure that
Box 1 Descriptions of the six domains of ‘good care’, as specified by the National Board of Health and Welfare

- Knowledge based healthcare that is fit for the purpose means that the care is to be science and evidence based, and designed to meet the needs of the individual patient in the best possible way.
- Safe health and medical care means that medical errors are prevented through an active programme of risk prevention.
- A patient focused health and medical care means that care is given with respect and sensitivity to the specific needs of the individual, and his or her expectations and values. These are to be considered when making clinical decisions.
- The term efficient health and medical care is used to denote the use of the available resources in the best possible manner, in order to achieve the goals that have been set. This means that the care is designed and provided in collaboration with stakeholders in the healthcare system, based on the degree of severity of the condition and the cost effectiveness of the measures.
- Equitable health and medical care means that the care is provided and distributed based on equal considerations for all.
- Health and medical care within reasonable time means that no patient needs to wait an unreasonable time for the care that he or she needs.

reflects quality and that can be used as the basis for operational development and for reporting the quality of health care.

The process of developing and using common QIs within specific domains will allow auditors to track the work and development of a single care unit, and to also measure and evaluate the care provided in a broader perspective. ‘Good care’ in the relevant context must be defined before QIs with quantitative measures can be developed. In order to be reliably measured, the QI should be scientifically reasonable and valid, and clearly defined.9 The metrics used to measure quality within the healthcare field are structured, process and outcome based. The goal is to measure the preconditions for good healthcare, the provision of care itself, including when, where and how it is provided, and the outcome of the care on the health and well being of patients (table 1).

QIs may refer to either general or specific actions taken by healthcare providers. A general action is one that is ‘valid for all types of health and medical care or nursing, independent of the disease or patient group or the specific actions taken’, and will be measured as a general QI, while a specific action is ‘related to a specific disease group or requirements group, or to a specific action taken’, and will be measured as a specific QI.9 The indicators can be placed within specific domains will allow auditors to track the care provided in a relevant context (table 1).9

Palliative care, like any other type of care, must satisfy the requirements for good care. Patients with palliative care needs are found in almost every healthcare setting, and this variety of places of care is one of the challenges to develop relevant indicators. There have been several attempts to define QIs for palliative care through methodologies using expert opinions as well as through bereaved family members.13–15

In 2009, work began on national clinical guidelines for palliative care in Sweden and a chapter about QIs was included. A research question was formulated during the work: ‘Which QIs for palliative care and end of life care are described in existing national policy documents in Sweden?’

Table 1 Definition of measures, as specified by the National Board of Health and Welfare, and the Swedish Association of Local Authorities and Regions

<table>
<thead>
<tr>
<th>Definition</th>
<th>Example from existing guidelines</th>
</tr>
</thead>
<tbody>
<tr>
<td>Structure measure</td>
<td>Reflects the preconditions available for good health and medical care/nursing</td>
</tr>
<tr>
<td>Process measure</td>
<td>Reflects the actual measures taken in care and nursing, when, where and how</td>
</tr>
<tr>
<td>Outcome measure</td>
<td>Reflects the results and effects of care and nursing on health and well being</td>
</tr>
</tbody>
</table>

MATERIALS AND METHODS

The report ‘National indicators of good care’,9 which describes indicators in published national guidelines, preliminary proposals and ongoing work, was reviewed to identify QIs for palliative care and end of life care. Guidelines for eight specific diseases10–12 16–18 and one overall guideline for cancer care11 were estimated as relevant for inclusion, as they related to diseases that are likely to lead to death. A manual search on the NBHW website in April 2010 showed one further guideline relevant to the question.19 A document describing QIs specific for the elderly20 was also included. It is recognised as a national guideline in the result.

The report entitled ‘End of life care’, published by the NBHW in 2006,21 was reviewed, especially the chapter describing existing regional and local clinical practice guidelines. Nine guidelines were identified,
two including palliative care for cancer patients. The other seven concern palliative care for any diagnosis. The care guidelines had been published and/or revised between 2002 and 2006. We searched for revisions and updates of the specified guidelines, contacting responsible individuals through email and telephone in May 2010. Two revised and one new regional clinical practice guideline were found (figure 1).

The annual report for 2010 for the Swedish Register of Palliative Care (SRPC) was also reviewed. In our review, a national guideline is defined as a document published by the government, in this case the NBHW, while clinical practice guidelines are written by the medical and nursing profession with knowledge in the field of palliative care. QIs were included whether or not they were described with a numerator and denominator. In the present report, it was not considered relevant to make a distinction between the concepts of palliative care and end of life care.

Since the review was performed, two new documents have been published in 2012: ‘A national knowledge based guidance for good palliative care’ including national guidelines (preliminary version) from the NBHW and ‘National clinical practice guidelines for palliative care 2012–2014’. They are not included in the result, but in the discussion section.

### RESULTS

#### QIs for palliative care and end of life care in national guidelines published by the NBHW

The total number of QIs found in the searched documents was 240, and of these 11 were distinct quality palliative care indicators (table 3). The palliative QIs were found in the five guidelines for cancer diseases and ‘The care and nursing for elderly’. Numerator and denominator were described for seven of them. The QIs relevant to palliative care and end of life care from the national guidelines are presented in their original wording (table 4).

There were 43 QIs specifically for cancer, but none of the QIs regarding breast cancer or colorectal cancer were relevant for palliative care. One of the seven indicators for prostate cancer was described as specific palliative—that is, the proportion offered radiation therapy for painful skeletal metastases. For lung cancer there were 26 indicators, three of which were specific for palliative lung cancer care. In addition to the cancer specific QIs, there were 10 overall indicators for cancer care, three of which were explicitly referred to end of life care: pain assessment, prescription of opioid for pain relief during end of life care and registration of deaths in SRPC. All guidelines for cancer diseases referred to these. Furthermore, the

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**Table 2** Definition of a quality indicator, as specified by the National Board of Health and Welfare, and the Swedish Association of Local Authorities and Regions

<table>
<thead>
<tr>
<th>Measure</th>
<th>Description</th>
<th>Measurement method</th>
<th>Data source</th>
<th>Source of error</th>
<th>Reporting</th>
<th>Target level</th>
<th>Stakeholder</th>
</tr>
</thead>
<tbody>
<tr>
<td>Content</td>
<td>Definition of the indicator in measurable terms</td>
<td>Description of numerator and denominator</td>
<td>Description of data collection method</td>
<td>Description of data source</td>
<td>Specification of any sources of error</td>
<td>Description of how data should be reported</td>
<td>Description of target levels</td>
</tr>
</tbody>
</table>

**Table 3** Quality indicators for palliative care from the guidelines of the National Board of Health and Welfare, and from ‘Care and nursing of the elderly’

<table>
<thead>
<tr>
<th>National guideline</th>
<th>No of QIs explicitly for palliative care and end of life care</th>
<th>Total No of QIs, including development indicators (n=240)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Asthma and COPD 2004</td>
<td>0</td>
<td>52</td>
</tr>
<tr>
<td>Breast cancer care 2007</td>
<td>3 general and common for cancer</td>
<td>5</td>
</tr>
<tr>
<td>Cardiac care 2008</td>
<td>0</td>
<td>41</td>
</tr>
<tr>
<td>Care and nursing of the elderly 2009</td>
<td>3</td>
<td>18</td>
</tr>
<tr>
<td>Colorectal cancer care 2007</td>
<td>3 general and common for cancer</td>
<td>7</td>
</tr>
<tr>
<td>Dementia care 2009</td>
<td>0</td>
<td>20</td>
</tr>
<tr>
<td>Diabetes care 2010</td>
<td>0</td>
<td>24</td>
</tr>
<tr>
<td>Lung cancer care 2010</td>
<td>4+3 general and common for cancer</td>
<td>26</td>
</tr>
<tr>
<td>Overall indicators for cancer care 2007</td>
<td>3 general and common for cancer</td>
<td>10</td>
</tr>
<tr>
<td>Prostate cancer care 2007</td>
<td>1+3 general and common for cancer)</td>
<td>5</td>
</tr>
<tr>
<td>Stroke care 2009</td>
<td>0</td>
<td>32</td>
</tr>
</tbody>
</table>

COPD, chronic obstructive pulmonary disease; QI, Quality indicators.
Table 4  Quality indicators for palliative care as described in national guidelines for breast, colorectal and prostate cancer care (including overall indicators for cancer care),17 national guidelines for lung cancer care18 and national quality indicators, and ‘Care and nursing of the elderly’.20

<table>
<thead>
<tr>
<th>Specific indicators for palliative care (translated verbatim)</th>
<th>Found in national guidelines/national quality indicators</th>
<th>Measure referred to numerator/denominator</th>
<th>Quality area referred to</th>
</tr>
</thead>
<tbody>
<tr>
<td>Age normalised incidence of palliative radiation therapy for skeletal metastases in prostate cancer</td>
<td>Prostate cancer care</td>
<td>Process measure</td>
<td>Patient focused health and medical care</td>
</tr>
<tr>
<td>Palliative radiation therapy for incurable lung cancer</td>
<td>Lung cancer care</td>
<td>Process measure</td>
<td>Equitable care</td>
</tr>
<tr>
<td>Palliative chemotherapy for lung cancer</td>
<td>Lung cancer care</td>
<td>Process measure</td>
<td>Equitable care</td>
</tr>
<tr>
<td>Stent in case of vena cava superior syndrome</td>
<td>Lung cancer care</td>
<td>Process measure</td>
<td>Equitable care</td>
</tr>
</tbody>
</table>

**General indicators for palliative care**

- Guidelines and procedures used for end of life care and nursing that describe, among other things, how informed counselling can be offered to terminally ill people aged 65 years and older. Care and nursing of the elderly. Not specified. Patient focused health and medical care.
- Fraction of people aged 65 years and older who have died, for whom pain was estimated with the aid of a scientifically evaluated instrument such as an NRS or a VAS, during the final week of life. Care and nursing of the elderly. Not specified. Numerator and denominator described. Patient focused health and medical care.

NRS, numeric rating scale; VAS, visual analogue scale.

measure ‘Documentation of the patient’s transition to palliative care’ was suggested as a development indicator in the guideline for lung cancer because of the importance for both patient and caregiver to be aware of the transition from life prolonging treatment to palliative care.

The document ‘Care and nursing of the elderly’ contained 18 QIs, three of which are used explicitly during the palliative phase. None of the remaining five national guidelines included indicators that could be applied to palliative care (table 4).

**QIs for palliative care in regional clinical practice guidelines for palliative care**

The most common indicator in regional clinical practice guidelines for palliative care was registration in the SRPC. As part of the report published by the NBHW ‘End of life care’,21 county councils and regions were questioned about the availability of clinical practice guidelines for palliative care. Nine were identified, two of which comprised palliative care for cancer patients. The other seven concerned palliative care for any diagnosis. The guidelines had been published and/or revised between 2002 and 2006. The report from the NBHW21 concluded that only one of the guidelines, ‘VILA, Clinical guideline for the Möln达尔 area’,24 addressed follow-up and development of quality. The guideline has a chapter with suggestions on standards for quality measures, such as pain assessment. Numerator and denominator were not defined for the QIs.

The search for revisions and updates in May 2010 showed two revised and one new regional clinical practice guideline. One of the revised guidelines
recommended registration in the SRPC as a QI and the other one had no quality indicator. The new clinical guideline recommended the same overall QIs as for cancer diseases, explicitly referred to end of life care: pain assessment, prescription of opioid for pain relief during end of life care and registration of deaths in the SRPC.

QIs for palliative care in the SRPC
The SRPC was established in 2005 as a national quality register with the aim of improving end of life care across all domains by identifying areas in which the quality of care can be improved. Registration takes place online after the death of the patient and is intended to reflect the quality of care during the patient’s last days or weeks. The SRPC annual report for 2010 included the three QIs for palliative care and end of life care that apply to all types of cancer care as well as the general indicators described in ‘Care and nursing of the elderly’. The QIs were: the patient and the relatives have been informed of the situation, the patient’s pain and other symptoms have been relieved, injectable medication is available, the patient has been given the opportunity to die in a place of his or her choosing and does not need to die alone, and the relatives have been offered bereavement counselling/support. Numerator and denominator were not defined for the QIs in the report.

DISCUSSION
In our review of Swedish policy documents, we identified 11 QIs for palliative care and end of life care out of a total of 240. Of these, three were explicitly related to end of life care: use of a numeric rating scale (NRS) for assessment of pain, registration in the SRPC and prescription of an injectable opioid as required. Disease specific indicators for palliative care are increasingly being described for various types of cancer, as related to specific therapeutic interventions. It is questionable if the suggested interventions (radiation therapy, chemotherapy and stent) (table 4) are disease specific QIs and if they are relevant for end of life care. However, it is a positive trend that measures for palliative care are described in guidelines for specific diseases. Palliative care is also addressed through analysis of the care of the elderly using three indicators, mainly related to information to be given to the patient and the family but also assessment of pain. In the

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Figure 1 Flowchart of the search for quality indicators. NBHW, National Board of Health and Welfare.
national guidelines for cardiology, pulmonary diseases, stroke, diabetes and dementia, there were no indicators relevant for palliative care or end of life care.

Quite a few of the QIs in the Swedish guidelines (11/240) are relevant for palliative care and end of life care, but it is more than Raijmakers et al found in their update of national guidelines. In the national guidelines of four countries, they found one QI relevant for care of cancer patients in their last days of life. One explanation is probably their definition of a QI (it should contain a numerator, denominator, cut-off point and address care in the last days of life) while our inclusion was much broader.

One of the described indicators, pain assessment by NRS, is specified as both a process and a structure indicator, while the others relate to process indicators. NRS for pain can also be used as a measure for an outcome indicator. This confirms the results of two international reviews of QIs for palliative care (by Ostgathe and Voltz, and by Pasman et al). Pasman et al found 142 palliative care indicators, most of which were process indicators with 57 outcome measures (two related to both process and outcome). Only five were structure measures. Both Pasman et al and Ostgathe and Voltz use the eight domains that the National Consensus Project has defined as important at the end of life. Most of the measures described in the reviews reveal the physical, structural and process aspects of the care. This is consistent with the above results.

There is a tendency to classify palliative care indicators in different ways in the documents that have been examined. Pain assessment, for example, which is found in two documents, relates to knowledge based and appropriate health and medical care in one case, and in another to the quality area of patient focused and appropriate health and medical care.

During 2012, the NBHW published ‘A national knowledge based guidance for good palliative care’ including national guidelines (preliminary version). They suggest nine QIs, six of which are possible to measure today. One QI is specified as a structure indicator (registration in the SRPC) and one as an outcome indicator (assessment of oral health). The remaining four are described as process indicators: two or more inpatient care admissions during the past 30 days, occurrence of pressure ulcers, prescription of opioid as required and prescription of anxiolytic as required. According to Raijmakers et al, an expert panel rated avoiding inpatient care during the past 30 days as a good descriptor of quality of care in the last days of life.

National clinical practice guidelines for palliative care 2012-2014 was published in March 2012, before the document from the NBHW, and refer to the SRPC and the general QIs for palliative care and end of life care in existing guidelines. Hopefully relevant indicators for end of life care can be described in more detail in the next version of the clinical practice guidelines.

The proposals of the SRPC, the national clinical practice guidelines for palliative care 2012-2014, ‘A national knowledge based guidance for good palliative care’ (preliminary version), the results of the present work and the articles by Ostgathe and Voltz and Pasman et al are consistent, and suggest that the development of general palliative care indicators in Sweden would lead to specification and validation of the existing indicators so that they become useful within care and nursing, across all diseases and sites of care. New indicators should be developed gradually, mainly within the areas that currently lack any indicators, such as the social and cultural aspects of care. We hope that such a development will inspire further work with specific palliative care measures within diseases other than cancer.

CONCLUSION

There is a lack of clinically relevant and feasible QIs for palliative care and end of life care in existing Swedish national guidelines for many different diseases.

To increase the quality of care in a patient as well as from a caregiver and organisational perspective, it is important to continue the work to develop and define general as well as specific QIs. This is relevant for different palliative care contexts, including a variety of diseases other than cancer and geriatric conditions. National and international consensus would support the opportunity to benchmark and exchange experience.

Contributors All authors were part of the conception and design of the study (SL and CJF), or analysis and interpretation of the data (SL, CJF, JA and BA), drafting the article or revising it critically for important intellectual content (SL, CJF, JA and BA), and final approval of the version to be published (SL, CJF, JA and BA).

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