



Postprint Version	1.0
Journal website	http://dx.doi.org/10.1016/j.jpainsymman.2010.10.267
Pubmed link	http://www.ncbi.nlm.nih.gov/pubmed/21429703
DOI	10.1016/j.jpainsymman.2010.10.267

This is a NIVEL certified Post Print, more info at <http://www.nivel.eu>

A New Set of Quality Indicators for Palliative Care: Process and Results of the Development Trajectory

SUSANNE J.J. CLAESSEN, MD, ANNEKE L. FRANCKE, RN, PHD, HELLA E. BELARBI, RN, PHD, H. ROELINE W. PASMAN, PHD, MARIANNE J.A. VAN DER PUTTEN, MSc, AND LUC DELIENS, PHD

Department of Public and Occupational Health (S.J.J.C., A.L.F., H.R.W.P., L.D.), EMGO Institute for Health and Care Research, VU University Medical Center, Amsterdam; NIVEL, Netherlands Institute for Health Services Research (S.J.J.C., A.L.F., H.E.B.), Utrecht; and Netherlands Health Care Inspectorate (M.J.A.P.), The Hague, The Netherlands; and End-of-Life Care Research Group (L.D.), Ghent University and Vrije Universiteit Brussel, Brussels, Belgium

ABSTRACT

Context: In some countries (the United States in particular), quality indicators for palliative care have already been developed. However, these quality indicators often cover one specific setting or target group, for example, palliative cancer care or palliative home care.

Objectives: This article describes the development and initial testing of a set of quality indicators for palliative care, applicable for all settings in which palliative care is being provided for adult patients in the Netherlands.

Methods and Results: In the first phase of the project, an inventory was made of existing relevant quality indicators. Most quality indicators focused on the process or outcome of palliative care, and quality indicators for the structure of palliative care were rare. Most of the existing quality indicators fall within the domain of physical care, and very few concern the social and spiritual domains of palliative care. In the second phase, a new draft set of quality indicators was developed. In addition to the previous inventory of existing indicators, interviews with patients, relatives, and caregivers provided input for the development of the draft set. Drafts of the set were tested among experts. In the third phase, the feasibility and usability of a draft set was established in 14 Dutch care organizations providing palliative care.

Conclusion: As a result of these phases, a set of quality indicators for palliative care has been developed, consisting of 33 indicators for palliative patient care and 10 indicators for support for relatives before and/or after the patient's death.

INTRODUCTION

In palliative care, the quality of life of patients and their families is greatly influenced by the quality of the care that is provided. To improve palliative care wherever needed, the quality of the care has to be assessed and monitored over time. Quality indicators may play an important role in this regard. In this article, we define quality indicators as “measurable aspects which give an indication of the quality of care, and which concern the structures, processes or outcomes of care.”¹ Structure indicators refer to the organization of the care (e.g., whether a care organization has a multidisciplinary palliative care team), whereas process

indicators refer to the quality of the care process (e.g., whether professionals work according to specific clinical guidelines). Outcome indicators often concern the clinical outcomes of care, for instance, the percentage of patients with (un)relieved pain or other symptoms.² The percentage of patients with positive or negative opinions about the quality of the care is another example of an outcome indicator. Prominent policy reports and publications on palliative care indicate that there is increasing interest in the development and use of quality indicators. For instance, the Council of Europe³ stated in 2003 that “the definition and adoption of indicators of good palliative care assessing all dimensions of care from the perspective of the patient should be encouraged.” Recently, the Council of Europe in 2009 reconfirmed this point of view and pleaded for the identification of practical indicators that can be used to check what progress has been made in patient care over a given period. Moreover, in the past decade, a variety of research publications have focused on quality indicators for palliative care. For example, Earle et al.^{4,5} and Grunfeld et al.⁶ described indicators for assessing the quality of end-of-life care for patients with cancer, and Twaddle et al.⁷ described quality indicators for palliative care in academic medical centers. In Italy, Peruselli et al.⁸ developed quality indicators for palliative home care. In The Netherlands, interest in quality indicators also has increased. In several subsequent policy statements, the Dutch Ministry of Health^{9,10} has stressed the need to develop and implement quality indicators. In line with this, the Ministry commissioned the development of a set of quality indicators for palliative care that should be applicable for all different settings of palliative care: not only at home, in hospices, and in palliative units but also in hospitals, nursing homes, homes for the elderly, mental health institutions, and institutes for the mentally retarded. It also was stipulated that the set should primarily consist of outcome indicators because the Ministry considers that the care organizations are responsible for organizing the structure and process of the care they provide, ensuring that the outcomes for patients and relatives are good. The set of indicators should not only be applicable for internal use within a health care organization but also should have the potential to be applicable for external use. Internal use means that care organizations use the indicators to assess the quality of the care they provide and subsequently to make quality improvements within their organization, where needed. External use means that the indicators (also) can be used to provide transparent quality information for external parties, such as patient organizations and the Health Care Inspectorate. The purpose of this article is to describe the development and initial testing of this new set of quality indicators, which had to be applicable in all settings where palliative care is being provided for adult patients in The Netherlands. The following main research questions will be addressed:

1. Which quality indicators for palliative care have previously been developed?
2. What are the characteristics of the new set of quality indicators?
3. Is this set feasible and usable in various palliative care settings?

METHODS AND RESULTS

The development of the set of quality indicators was characterized by a phased approach, which is presented in Table 1. The project was carried out over a two-year period, namely in 2007 and 2008.

Phase 1: Inventory

National Inventory.

In the first half of 2007, several sources were searched to obtain relevant indicators in the Dutch language, for instance, Web sites focusing on palliative care (e.g., www.ikcnet.nl; www.palliatief.nl), the library catalog of The Netherlands Institute for Health Services Research (NIVEL), and documents suggested by experts. This resulted in 94 potentially relevant documents, which were analyzed by one of the authors (H. E. B.) based on a schedule with questions including the type of document (e.g., concerning indicators, clinical guidelines, or quality instruments), the quality aspects described, the aim, the target group, and the organizational setting. The most important conclusion that could be drawn from the national inventory was that, in The Netherlands, there are many clinical guidelines and other quality-related documents concerning palliative care. However, none of these guidelines or documents describes quality indicators for palliative care in detail. One general quality indicator set was found,¹¹ but this set was not specific for palliative care.

International Systematic Review.



In the second half of 2007, we also systematically searched several international databases, including PubMed, PsycINFO, EMBASE, and CINAHL. Keywords and medical subject headings for palliative care and quality indicators were combined. Detailed information about the search strategy has been published elsewhere.² For this international systematic review, we applied the following inclusion criteria: 1) the focus in the literature to be reviewed had to be on the description or development of specific quality indicators for palliative care; and 2) the description of the indicator involved a numerator and a denominator, or the numerator and denominator could be directly deduced from the description of the indicator, or a performance standard was given. The searches resulted in 650 potentially relevant references. Subsequently, a selection was made on the basis of the title and/or abstract of the 650 references, according to the inclusion criteria. This resulted in 33 potentially relevant references. Second, the full text of each reference was read, after which the reference was finally excluded or included on the basis of the inclusion criteria. This final selection resulted in 16 publications, mainly originating from the United States (among which was an Agency for Healthcare Research and Quality contribution¹²), meeting the inclusion criteria. They described a total of 142 quality indicators. In a subsequent analysis, the main characteristics of the indicators were extracted. Finally, a methodological analysis was performed, with the AIRE instrument (Appraisal of Indicators through Research and Evaluation) instrument.¹³ The AIRE instrument is meant to assess whether the aim and the organizational context of the quality indicators are clearly described and whether the quality indicators are research based. One conclusion of the review was that most of the indicators were process indicators (n = 82) and outcome indicators (n = 57), and far fewer structure indicators (n = 5) were found. Indicators concerning the social and spiritual aspects of palliative care were underrepresented. Another conclusion was that many of the existing indicators applied to only one specific setting or target group.^{4-8,14-20} The scores, according to the AIRE instrument, showed that the methodological quality of the indicators varied. Some sets had clearly defined numerators, denominators, and/or performance standards, whereas the content of other sets was not described in detail. More details of the methods and results of the systematic review have been published elsewhere.²

Phase 2: Development and Testing Draft Sets Consultation of Expert Panel.

An essential stage in the development of the set of quality indicators was the consultation of 36 experts, representing medical practice, research, and palliative care policy making. This was considered to be important because the indicators were intended to reflect, as much as possible, the experiences of target groups, and we expected that this would enhance acceptance in the field of palliative care. The expert meeting was held at the end of 2007. A classification scheme of existing indicators derived from the national inventory or from the systematic international review was sent to the experts before the meeting.^{21,22} The experts were asked to prioritize themes for indicators and also determine which existing quality indicators reflected these themes the most, in view of their applicability and relevance for the Dutch situation. Furthermore, they were asked to indicate which quality indicators were missing. After the meeting, the researchers analyzed the reactions of the experts and subsequently developed a new draft set of indicators. This new draft set was then sent by e-mail to the experts, and they were asked to comment again on the indicators and the classification.

Focus Groups and Interviews.

Subsequently, several focus group and individual interviews were held with patients, relatives, and caregivers. The aim of the interviews was to investigate essential components of quality of care from a user perspective, so that these could be taken into account in the development of the set of indicators. Mid-2008, two focus group interviews were held with a total of 18 caregivers (mainly nurses and volunteer care providers). There was also one focus group interview with three relatives of patients who had recently died after a long period of illness. Furthermore, three patients and one relative were individually interviewed. Various inpatient and outpatient settings were represented in the interviews. All focus group discussions and interviews had an “open approach,” in the sense that we initiated the focus group discussions with open-ended questions, such as “Describe some positive and negative care experiences” and “According to you, what makes good quality care?” The patients and relatives were asked to answer from their own perspective, whereas professional and volunteer care providers were asked to identify with the needs and wishes of patients and relatives. The interviewed patients, relatives, and care providers were not asked to assess existing quality indicators (in contrast to the experts in the foregoing subphase). The main reason

was that we did not want to influence the participants too much by letting them know what quality indicators already existed. The individual interviews were recorded and typed verbatim. The focus group interviews were not all typed out but were summarized in sheets in dialog between the participants. The transcribed interviews and sheets were then analyzed qualitatively by the first author. She read and reread the material and inductively coded the aspects of care that were mentioned as crucial for high-quality palliative care. Subsequently, the findings from the interviews performed in 2008 were compared and combined with the findings of qualitative interviews with 19 patients and 23 relatives in a previous study carried out in 2000 by our research group. These previous interviews also focused on what care users find important for high-quality palliative care.²³ The process and outcomes of the analysis were discussed by the first author and the coauthors. Important quality aspects that emerged from the analysis, and which were frequently mentioned in the interviews, were “taking wishes and needs into consideration (autonomy),” “personal/warm attention,” and “expertise and continuity of caregivers.” These quality aspects were somewhat underexposed in the themes and the indicators identified in previous phases. At the end of this phase, we ensured that the issues mentioned in the interviews were reflected in several indicators in the draft set.

Testing Different Drafts in the Steering Committee.

On several occasions during the development, the draft sets were discussed with the steering committee, which consisted of various stakeholders, for example, representatives from patient organizations, national umbrella organizations in the field of palliative care, the Ministry of Health, and the Health Care Inspectorate. The main task of the steering committee was to reflect on the draft sets. One of the points of interests mentioned repeatedly by the steering committee was that, if possible, the quality indicators should be assessed from the perspective of the patients or the relatives, rather than from the perspective of the caregivers. Furthermore, the steering committee often emphasized that patients, as well as relatives and health care providers, must not be burdened with too many questions. This implied that the set of indicators should not be too extensive.

[TABLE 1]

Phase 3: Testing in Daily Practice

Aim of the Testing Phase.

During a two-month period (end of 2008), the indicator set was tested for feasibility and usability in practice. Feasibility was measured by taking into account the time investment for the health care professionals, patients, and relatives involved. In addition, feasibility was measured by taking into account the availability of contact persons/ caregivers who wanted to work with the indicators and availability of patients and relatives in whom the indicators could be measured during a rather limited measurement period (± 2 months). Usability concerns the extent to which the results of the indicator can be applied.²⁴ Therefore, we took into account the perception of the health care professional, that is, the quality indicator assessments can be used as input for quality improvements. Usability also refers to the usability of the instruments used to measure the quality indicators (e.g., whether or not they are too extensive for this vulnerable group). These aspects concerning feasibility and usability were measured in patients, relatives, and/or contact persons from the care organizations.

Recruitment.

Fourteen Dutch care organizations formed a convenience sample and participated in the assessment. These care organizations were recruited through personal contacts of the research partners (NIVEL and EMGO Institute). They were purposively chosen because we aimed to recruit (at least one) representative care organizations for each of the following care settings: palliative home care, hospice care, palliative hospital care, palliative day-care, palliative care in a nursing home or home for the elderly, and palliative care in an institute for the mentally retarded or mental health institution. Within the 14 participating care organizations, all patients or relatives who met the inclusion criteria were invited to participate. The inclusion criteria for patients were a maximum life expectancy of six months or less and/or receiving

palliative treatment. The inclusion criteria for relatives were: directly involved in the care for patients who had died after a long illness (i.e. not suddenly) between six weeks and six months previously.



Assessment of the Quality Indicators.

About half of the 43 quality indicators in the draft set concerned the experiences of patients or relatives with the care received. These indicators were measured with the CQ-index Palliative Care (CQ-index PC). This is a structured questionnaire containing questions on care experiences. 25 The CQ-index PC consists of a patient version and a relative version. The relatives, as well as patients living at home, received the questionnaire by post, and patients in inpatient or hospice settings responded to the questionnaire verbally during an interview conducted by the researchers or trained interviewers. The patients were asked to complete the CQ-index PC based on their experiences with the care delivered in the previous week by the care institution from which they received the questionnaire. Bereaved relatives who received the CQ-index PC relative version were asked to complete the questionnaire by taking into account the care received from the last health care institution involved. The other half of the set concerned quality indicators about the prevalence of symptoms, that is, pain, fatigue, shortness of breath, constipation, anxiety, or feeling depressed. These quality indicators were measured with numerical rating scales (NRSs), ranging from zero to 10.²⁶ The NRSs were completed by the patients and administered by a caregiver (often a nurse). For patients with moderate or severe cognitive impairments, NRSs were not used but observation scales that are appropriate for this target group.²⁷ In principle, the patients who were involved in the assessment of the indicators regarding care experiences were the same as those who were involved in the assessment of indicators regarding the prevalence of symptoms. Table 2 presents the number of patients and relatives who participated in the testing phase. We did not get the impression that the patients or the relatives felt emotionally or physically burdened by the assessments, although some found the length of the CQ-index PC-the instrument used to measure the quality indicators for care experiences-too long. This critical comment made by about half of the respondents was the main reason why we subsequently shortened the CQ-index.²⁵ This testing phase also indicated some organizational factors that contribute to the successful application of quality indicators. One success factor is the provision of good information for caregivers about the aim of the assessments, instructions, and how to measure the quality indicators. Moreover, the availability of one contact person (e.g., a nursing manager or team coordinator) within the organization is crucial. For the recruitment of relatives after the death of a patient, it is also important that there is an updated list of the addresses of all relatives.

[TABLE 2]

Evaluation Among Contact Persons.

The contact persons in the participating care organizations all received a short report on the results of the quality indicator assessments, after which they completed an evaluation questionnaire. Subsequently, verbal open interviews were held with these contact persons. Both the evaluation questionnaire and the interview focused on aspects of feasibility and usability. The contact persons reported that their time investment had been feasible, and some mentioned that they had deduced improvements from the report, for example, regarding aftercare for relatives. It appeared that relatives were not always informed about the possibilities of aftercare. Finally, all contact persons in the participating care organizations were invited to attend an evaluation meeting. The discussions in this meeting also showed that, in general, the contact persons were positive about the usability of quality indicators because the assessments had provided more insight into the quality of the care. However, some of them pointed to the fact that the indicators concern multidisciplinary care. As a consequence, it was sometimes unclear which health care provider was responsible for low scores for certain quality indicators. It was concluded that quality indicators only give an indication of good or bad quality care, and that when scores are low, additional inquiries must be made to find out where things go wrong in the multidisciplinary chain of palliative care.



Phase 4: Final Adjustments of the Quality Indicator Set

After the testing phase, the findings were discussed with the steering committee. These discussions led to some adjustments of the quality indicator set. For example, we reformulated the draft indicator “The extent to which patients received information regarding life expectancy” because it turned out that some patients had difficulties with the underlying question about life expectancy. Therefore, we changed the indicator to “The extent to which patients receive information about the expected course of the illness.” Furthermore, some indicators were omitted (i.e., the indicator “The extent to which patients experience the meals as good”) because these were not very specific for palliative care. The final set now consists of 43 (mainly outcome) indicators, most of which (33 indicators) concern the palliative care provided for the patients, and the rest (10 indicators) concern support and aftercare for the relatives. The final set of quality indicators is described in more detail below.

Description of the Quality Indicator Set

The set of quality indicators for palliative care is subdivided into the following main categories:

Quality Indicators Concerning Palliative Care for Patients

1. Management of pain and other physical symptoms
2. Care for psychosocial well-being
3. Care for spiritual well-being
4. General aspects

Quality Indicators Concerning Support or Aftercare for Relatives

5. Care for psychosocial and spiritual wellbeing of relatives
6. General aspects
7. Aftercare

Quality indicators concerning the prevalence of symptoms are expressed as “The percentage of patients ... and so on ...,” with numerators and denominators. Quality indicators concerning actual care experiences, measured with the CQ-index PC, are mostly expressed as “The extent to which patients ... and so on....” In these quality indicators, no numerators or denominators are presented because they are assessed by calculating scale means (and not percentages). Tables 3 and 4 present two examples of quality indicators (translated from Dutch). All the quality indicators that have been developed are outcome indicators, except one: the indicator “Presence of documentation concerning the desired care and treatment at the end of life” (Table 5). The examples above provide insight into various elements of the quality indicators. It is beyond the scope of this article to describe all 43 quality indicators in detail (including numerators, denominators, source of registration, and registration questions), but the entire set of quality indicators (translated from Dutch into English) is available on request. Tables 5 and 6 present an overview of the titles of the quality indicators for palliative care for patients and relatives in categories.

[TABLE 3, 4, 5]

DISCUSSION

Currently, there is increasing interest in quality indicators for palliative care. In the international systematic review that we conducted at the end of 2007, 16 publications were selected, describing a total of 142 quality indicators.² Since then, there have been several new publications concerning quality indicators for palliative care.^{24,28e36} Most of these sets of quality indicators focus on the structure or process of care, whereas our set primarily focuses on outcomes. Measuring structure or process indicators may be easier and cheaper than measuring outcome indicators because the relevant information can often be obtained from medical charts or administrative databases, whereas outcome indicators often have to be derived from the individual care users. However, in our opinion, the perspectives of care users on the outcomes of care provide the best indications whether good quality care has been achieved. Another difference between our set of indicators and most other sets concerns the fact that the latter are often targeted to specific populations in palliative care, such as patients with incurable cancer.^{12,24,29,31e35} In the case of cancer



patients, many quality indicators focus on specific types of treatment (e.g., chemotherapy) and the side effects thereof, which make them less suitable for use in other patient groups. Characteristic for our set is that the indicators are applicable in all settings and for all adult patient groups receiving palliative care. Also characteristic for our set is that the indicators not only address physical, psychosocial, and spiritual domains but also aftercare. Most other quality indicator sets mainly focus on physical aspects, and the social and spiritual aspects of palliative care are often underrepresented.² To the best of our knowledge, such a broad generic set of quality indicators, which can be used in various settings, is unique. However, in this project, the set has not yet been tested in palliative care facilities for children because we considered palliative care in children as a very specific field. More research must be carried out to provide insight into which indicators in the set should be adapted, omitted, or added for use in palliative care settings for children. Another limitation is that the set was tested in a rather small sample of 14 care organizations. Therefore, in a planned future research project, the set of indicators also will be tested for usability and feasibility in a larger sample. In a future study, we also will establish whether the set is not only suitable for internal use by care providers but also for external parties who want to have public comparative information. Comparing the quality indicator scores of different care providers can be relevant for the Health Care Inspectorate, patient organizations, or health care insurers wanting to know where the best (or worst) palliative care is provided. But before using the set for public comparisons, we first have to assess significant “case mix adjusters” and the discriminative power of the indicators. Only if future research in a larger sample establishes that the indicators do have discriminative power will we recommend their use for public comparative information (benchmarking). In the planned future research project, we also will assess “best practice norms” for specific palliative care settings. These are relative norms derived from the scores of the best scoring care providers (e.g., the upper quartile).¹¹ The main reason for choosing relative best practice norms, instead of absolute norms, is that relative norms are realistic and, therefore, motivate health care professionals to improve the quality of the care they provide.

[TABLE 6]

CONCLUSION

At the end of this development phase, a set of 33 quality indicators for patients and 10 for relatives is now available. This set covers all aspects of palliative care: physical, psychosocial, and spiritual care, including the support for relatives. At the moment, the set is suitable for internal use by health care organizations in various palliative care settings. Future research will establish whether the set is also appropriate for external use.

DISCLOSURES AND ACKNOWLEDGMENTS

This project was funded by The Netherlands Organization for Health Research and Development (ZonMw). The authors have no conflicts of interest to disclose. The authors would like to thank the contact persons in the 14 care organizations that participated in the test phase, as well as all the patients and relatives who took part. We also thank The Netherlands Organization for Health Research and Development (ZonMwprogramme Palliative Care) for the project grant.

REFERENCES

1. Campbell SM, Braspenning J, Hutchinson A, Marshall MN. Improving the quality of health care. Research methods used in developing and applying quality indicators in primary care. *BMJ* 2003;326:816e819.
2. Pasman HRW, Brandt HE, Deliëns L, Francke AL. Quality indicators for palliative care: a systematic review. *J Pain Symptom Manage* 2009; 38:145e156.
3. Council of Europe. Recommendation Rec (2003) 24 of the Committee of Ministers to member states on the organisation of palliative care. CM 2003:130.
4. Earle CC, Neville BA, Landrum MB, et al. Evaluating claims-based indicators of the intensity of end-of-life cancer care. *Int J Qual Health Care* 2005;17:505e509.
5. 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: 1133e1138.

Claessen, S.J.J., Francke, A.L., Belarbi, H.E., Pasman, H.R.W., Putten, M.J.A. van der, Deliëns, L. A new set of quality indicators for palliative care: process and results of the development trajectory. *Journal of Pain and Symptom Management*: 2011



6. 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;20:769e777.
7. Twaddle ML, Maxwell TL, Cassel JB, et al. Palliative care benchmarks from academic medical centers. *J Palliat Med* 2007;10:86e98.
8. 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;13:34e42.
9. Plan van aanpak Palliatieve zorg 2008e2010 (Plan for Palliative Care [in Dutch]). The Hague, The Netherlands: Ministry of Health, Welfare and Sports, 2008.
10. Voortgang en verdere verbetering palliatieve zorg (Progression and further improvement of palliative care [in Dutch]). The Hague, The Netherlands: Ministry of Health, Welfare and Sports, 2002.
11. Actiz. Kwaliteitskader Verantwoorde zorg (Quality framework good care [in Dutch]). Utrecht, The Netherlands: Actiz, 2007.
12. Lorenz K, Lynn K. Cancer care quality measures. Symptoms and end-of-life care. Evidence Report/Technology Assessment No. 137. Report No. 06-E001. Rockville, MD: Agency for Healthcare Research and Quality, 2006.
13. de Koning J, Smulders A, Klazinga NS. Appraisal of Indicators through Research and Evaluation (AIRE) instrument. Amsterdam, The Netherlands: Academic Medical Center, 2006.
14. Anonymous. Assessing care of vulnerable elders-3 quality indicators. *J Am Geriatr Soc* 2007; 55(Suppl 2):S464eS487.
15. Keay TJ, Fredman L, Taler GA, Datta S, Levenson SA. Indicators of quality medical care for the terminally ill in nursing homes. *J Am Geriatr Soc* 1994;42:853e860.
16. 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): S318eS326.
17. 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): S404eS411.
18. 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: 264e271.
19. 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;5:310e319.
20. Wenger NS, Rosenfeld K. Quality indicators for end-of-life care in vulnerable elders. *Ann Intern Med* 2001;135(8 Pt 2):677e685.
21. Casarett DJ, Teno J, Higginson I. How should nations measure the quality of end-of-life care for older adults? Recommendations for an international minimum data set. *J Am Geriatr Soc* 2006;54:1765e1771.
22. de Graeff A, Hesselman GM, Krol RJA, et al. Palliatieve zorg. Richtlijnen voor de praktijk (Palliative care. Guidelines for practice [in Dutch]). Utrecht, The Netherlands: VIKC, 2006.
23. Francke AL, Willems DL. Palliatieve zorg vandaag en morgen: feiten, opvattingen en scenario's (Palliative care today and tomorrow: facts, views and scenarios [in Dutch]). Maarssen, The Netherlands: Elsevier Gezondheidszorg, 2000.
24. Seow H, Snyder CF, Mularski RA, et al. A framework for assessing quality indicators for cancer care at the end of life. *J Pain Symptom Manage* 2009;38: 903e912.
25. Claessen SJJ, Francke AL, Sixma H, et al. Op weg naar een CQ-index Palliatieve Zorg: meetinstrumentontwikkeling (Towards a CQ-index Palliative Care: Instrument Development [in Dutch]). Utrecht, The Netherlands: NIVEL, 2009.
26. Chang VT, Hwang SS, Feuerman M. Validation of the Edmonton Symptom Assessment Scale. *Cancer* 2000;88:2164e2171.
27. van Herk R, van Dijk M, Tibboel D, et al. The Rotterdam Elderly Pain Observation Scale (REPOS); a new behavioral pain scale for noncommunicative adults and cognitively impaired elderly. *J Pain Manag* 2008;1:367e378.
28. Pastrana T, Radbruch L, Nauck F, et al. Outcome indicators in palliative care: how to assess quality and success. Focus group and nominal group technique in Germany. *Support Care Cancer* 2010;18:859e868.
29. Finlay E, Shreve S, Casarett D. Nationwide veterans affairs quality measure for cancer: the family assessment of treatment at end of life. *J Clin Oncol* 2008;26:3838e3844.
30. Grunfeld E, Urquhart R, Mykhalovskiy E, et al. Toward population-based indicators of quality end-of-life care: testing stakeholder agreement. *Cancer* 2008;112:2301e2308.
31. Beccaro M, Caraceni A, Costantini M, ISDOC Study Group. End-of-life care in Italian hospitals: quality of and satisfaction with care from the caregivers' point of view: results from the Italian Survey of the Dying of Cancer. *J Pain Symptom Manage* 2010;39:1003e1015.

Claessen, S.J.J., Francke, A.L., Belarbi, H.E., Pasman, H.R.W., Putten, M.J.A. van der, Deliëns, L. A new set of quality indicators for palliative care: process and results of the development trajectory. *Journal of Pain and Symptom Management*: 2011

32. Miyashita M, Morita T, Ichikawa T, et al. Quality indicators of end-of-life cancer care from the Vol. - No. - 7 - 2011 A New Set of Quality Indicators for Palliative Care 13 bereaved family members' perspective in Japan. *J Pain Symptom Manage* 2009;37:1019e1026.
33. Seow H, Snyder CF, Shugarman LR, et al. Developing quality indicators for cancer end-of-life care: proceedings from a national symposium. *Cancer* 2009;115:3820e3829.
34. McNiff KK, Neuss MN, Jacobson JO, et al. Measuring supportive care in medical oncology practice: lessons learned from the quality oncology practice initiative. *J Clin Oncol* 2008; 26:3832e3837.
35. Lorenz KA, Dy SM, Naeim A, et al. Quality measures for supportive cancer care: the Cancer Quality-ASSIST Project. *J Pain Symptom Manage* 2009;37: 943e964.
36. Ostgathe C, Voltz R. Quality indicators in end-of- life care. *Curr Opin Support Palliat Care* 2010; 4:170e173.





Table 1
Overview of Project Stages

Phase	Aim and Approach	Results/Conclusions
Phase 1. Inventory National inventory of existing quality indicators and relevant documents	Several Dutch literature sources were searched to obtain relevant indicators in the Dutch language	A final set of 25 relevant quality documents were reviewed Conclusion: No Dutch quality indicators specifically focusing on palliative care existed
International systematic literature review on existing quality indicators	<p>*Several international databases (PubMed, PsycINFO, EMBASE, and CINAHL) were searched to track down indicators. Keywords and medical subject headings for palliative care and quality indicators were combined</p> <p>*First selection on basis of title and/or abstract, and second selection on basis of full text</p> <p>*Characteristics of indicators were extracted, and a methodological analysis was performed</p>	<p>16 publications were found, which described a total of 142 quality indicators for palliative care. Most were process indicators ($n=82$) and outcome indicators ($n=57$). Most indicators applied to only one specific setting or to very specific target groups</p> <p>The indicators identified in this international systematic review gave input to the expert meeting in the subsequent phase</p>
Phase 2. Development and testing draft set Expert meeting and subsequently expert round by e-mail	<p>Main aims of the meeting with 36 experts: to inform them about the project and to choose highly relevant themes and indicators. An overview of themes and existing indicators was sent before the meeting. The experts were asked:</p> <p>*to prioritize themes for indicators</p> <p>*to indicate which themes or indicators were missing</p> <p>After the meeting, an overview of the themes and indicators, which were given high priority was sent by e-mail to the experts. They were asked to comment again on the prioritized themes and indicators</p>	<p>*The themes "pain" and "fatigue/insomnia" were considered highly relevant, as well as the themes "anxiety," "depression/sombrenness," and "adequacy of information and communication"</p> <p>*Experts missed indicators for aftercare</p> <p>*Experts also indicated that some existing international quality indicators were relevant but have to be adapted to fit with our project to result in indicators that can be used in all settings of palliative care. This expert advice prompted our decision to develop a new set of quality indicators</p>
Focus group interviews and/or individual interviews with patients, relatives, and caregivers	<p>To determine essential components of quality of care:</p> <p>*two focus group interviews were held with a total of 18 healthcare providers, and one focus group with three bereaved relatives</p> <p>*individual interviews were held with three patients and one relative. In the analysis, these interviews were combined with findings of previous interviews with 19 patients and 23 relatives</p>	<p>Important quality aspects that were frequently mentioned were: respect for autonomy, personal/warm attention from care providers, and expertise and continuity of caregivers</p> <p>These quality aspects were somewhat underexposed in the themes and indicators prioritized in previous phases, so these additional themes were integrated in the draft set of indicators</p>
Testing drafts in the steering committee	On several occasions during the project, the steering committee, consisting of various stakeholders, met. A main task of this committee was to reflect the draft set of indicators	A main comment of the steering committee was that most quality indicators should concern the perspective of the patients or the relatives, rather than the perspective of caregivers. They also recommended a rather short set because patients, relatives, and care providers must not be burdened by the assessments

(Continued)



Table 1
Continued

Phase	Aim and Approach	Results/Conclusions
Phase 3. Testing in daily practice Measurement of indicators	<p>During a two-month period, the draft set was tested for feasibility and usability in different palliative care settings. Characteristics of the 14 participant institutions and the patients and relatives involved in this testing phase are presented in <i>Table 2</i>.</p> <p>A total of 43 quality indicators were measured distinguished in:</p> <ul style="list-style-type: none"> *indicators concerning actual care experiences of patients, measured with the CQ-index PC *indicators related to the prevalence of symptoms, measured with NRS *indicators concerning actual care experiences of relatives, measured with the relative version of the CQ-index PC 	For results/conclusions, see below
Evaluation of usability and feasibility of the measurements	<p>After the two-month-measurement period, contact persons (often nursing managers) completed a short evaluation questionnaire and participated in an open interview. The aim was to gain insight into the care providers perspective on the feasibility (e.g. time investment) and usability (e.g. whether the indicators can be used for quality improvement)</p> <p>The usability and feasibility of the quality indicator set was also discussed in a final group meeting with seven contact persons from the participating institutions and two other people</p>	<p>The contact persons reported that the time investment was feasible, for themselves and also for the patients. The quality indicator assessments had provided more insight into the quality of the care and also some necessary quality improvements</p> <p>The positive results of this testing phase, allowed us to proceed to the final phase in this development trajectory (see Phase 4)</p>
Phase 4. Final adjustments of the quality indicator set	<p>Some final adjustments were made. A main reason for adjusting a quality indicator was, for example, that members of the steering committee indicated that the description of some quality indicators was not specific enough for palliative care</p>	<p>The final set now consists of 43 (mainly outcome) indicators, of which 33 concern palliative care provided to patients and 10 concern support for relatives</p>



Table 2
Number of Patients and Relatives Who Participated in the Testing Phase

Setting	Patients Involved in the Assessment of Quality Indicators for Care Experiences	Relatives Involved in the Assessment of Quality Indicators for Care Experiences	Patients Involved in the Assessment of Quality Indicators for Symptoms
Two high-care hospices and one volunteer-driven hospice	8	28	8
One palliative care unit in a hospital	3	3	3
One palliative care unit in a nursing home and one in a home for the elderly	6	24	3
One home for the elderly and one nursing home (no palliative care unit)	3	11	3
Two cancer units in a hospital	8	0 (in these cancer units, addresses of bereaved relatives were unknown)	3
One home care organization	11	14	14
Two mental health institutions	1	1	1
One institute for the mentally retarded	0	4	10
Total	40	85	45

Table 3
Example of a Quality Indicator Concerning the Prevalence of a Symptom

Percentage of Patients with Moderate-to-Severe Pain	
Reason for indicator	Pain is a common symptom in the palliative phase. The quality of both pharmacological and nonpharmacological interventions influences the severity of pain
Numerator	The number of patients with a pain score of 4 or above on the NRS (average over three days)
Denominator	The total number of patients for whom this indicator is measured
Do not measure	Comatose and deeply sedated patients
Registration source: patients, according to their scores on the NRS described here	This indicator must be measured <i>on three consecutive days (1 × a day)</i> on a NRS. As far as possible, the measurements should take place at the same time each day (e.g., before the daily care rounds). The question is: Which score from zero to 10 would you give for pain? <i>The patient must decide on the score independently. If the patient's health status permits, the patient should preferably also hold the pen. A score list with NRS scales could also be left with the patient. This is, in particular, important for patients (e.g., living at home) who do not have daily contact with a care provider</i>
Registration of patients with cognitive impairments (e.g., patients with dementia or in institutes for the mentally retarded)	Pain can be measured in patients with moderate to (very) severe cognitive impairments but not with an NRS. Pain in these patients, can be measured with a pain observation instrument that was specifically developed for the measurement of patients with cognitive impairments, namely the Rotterdam Elderly Pain Observation Scale, see van Herk, 2008. ²⁷ Measurements with this instrument should also take place <i>on three consecutive days (1 × a day)</i> , for as far as possible at the same time each day (e.g., before the daily care rounds).



Table 4
Example of a Quality Indicator Concerning Actual Care Experiences

Extent to Which Patients Receive Support for Their Physical Symptoms	
Reason for indicator	Pain, fatigue, shortness of breath, and constipation are symptoms that frequently occur in the palliative phase. The quality of both pharmacological and nonpharmacological interventions influences the severity of a patient's physical symptoms
Do not measure	Patients with moderate to (very) severe cognitive impairments, young children, and comatose and deeply sedated patients
Registration source: items of the patient version of the CQ-index PC	<p>Do you receive support when you are in pain?</p> <p><input type="checkbox"/> never</p> <p><input type="checkbox"/> sometimes</p> <p><input type="checkbox"/> usually</p> <p><input type="checkbox"/> always</p> <p><input type="checkbox"/> not applicable (because I have no pain)</p> <p>Do you receive support when you are tired?</p> <p><input type="checkbox"/> never</p> <p><input type="checkbox"/> sometimes</p> <p><input type="checkbox"/> usually</p> <p><input type="checkbox"/> always</p> <p><input type="checkbox"/> not applicable (because I am not tired)</p> <p>Do you receive support when you have shortness of breath?</p> <p><input type="checkbox"/> never</p> <p><input type="checkbox"/> sometimes</p> <p><input type="checkbox"/> usually</p> <p><input type="checkbox"/> always</p> <p><input type="checkbox"/> not applicable (because I do not have shortness of breath)</p> <p>Do you receive support when you are constipated?</p> <p><input type="checkbox"/> never</p> <p><input type="checkbox"/> sometimes</p> <p><input type="checkbox"/> usually</p> <p><input type="checkbox"/> always</p> <p><input type="checkbox"/> not applicable (because I am not constipated)</p> <p><i>“Support” should be interpreted in the broadest sense of the word: it can sometimes mean the attention a patient receives from care providers, but it can also mean treatment with medication</i></p>



Table 5

Overview of Titles of Quality Indicators for Palliative Care for Patients, in Categories (translated from Dutch)

Category	Name Indicator	
A. Management of pain and other physical symptoms	A1. Percentage of patients with moderate to severe pain	
	A2. Percentage of patients with fatigue	
	A3. Percentage of patients with shortness of breath	
	A4. Percentage of patients with constipation	
	A5. Extent to which patients receive support for their physical symptoms (pain, fatigue, shortness of breath, and constipation)	
	A6. Extent to which patients receive help with physical care	
B. Care for psychosocial well-being	B1. Percentage of patients with anxiety	
	B2. Percentage of patients who feel depressed	
	B3. Extent to which patients receive support when they feel anxious or feel depressed	
	B4. Extent to which patients receive attention from their caregivers	
	B5. Extent to which patients are satisfied with the counseling aspects of "politeness" and "being taken seriously"	
	B6. Extent to which patients experience respect for their autonomy	
	B7. Extent to which patients experience respect for their privacy	
	B8. Extent to which direct relatives considered that the patient had the opportunity to be alone	
C. Care for spiritual well-being	C1. Extent to which patients indicate that caregivers respect their life stance	
	C2. Extent to which patients indicate that they have access to a counselor for spiritual problems	
	C3. Extent to which relatives indicate that the patient had access to a counselor for spiritual problems	
	C4. Extent to which relatives indicate that the patient received support with preparations for saying goodbye	
	C5. Extent to which patients indicate that they feel that life is worthwhile	
	C6. Percentage of relatives who indicate that the patient died peacefully	
	C7. Percentage of relatives who indicate that the patient had accepted her/his approaching death	
	C8. Extent to which relatives indicate that there was attention and respect for the psychosocial and spiritual well-being of the patient	
	D. Generic aspects	D1. Extent to which patients in the last month before their death were in the location of their preference
		D2. Percentage of patients who died in the location of their preference
D3. Extent to which patients know who the contact person is for the care		
D4. Extent to which patients receive information about the expected course of the illness		
D5. Extent to which patients receive information about the advantages and disadvantages of various types of treatments		
D6. Extent to which patients indicate that they receive understandable explanations		
D7. Extent to which patients indicate that they receive contradictory information		
D8. Presence of documentation concerning the desired care and treatment at the end of life		
D9. Extent to which relatives indicate that the patient was asked about her/his opinions with regard to end-of-life decisions		
D10. Extent to which patients experience the expertise and continuity		
D11. Percentage of patients who receive medical aids soon enough		



Table 6
Overview of Titles of Quality Indicators Concerning Support or Aftercare for Relatives, in Categories (translated from Dutch)

Category	Title Indicator
E. Care for psychosocial and spiritual well-being of relatives	E1. Extent to which, according to the direct relatives, attention was paid to their own psychosocial and spiritual well-being E2. Extent to which the direct relatives felt that they were treated well in all respects by the caregivers E3. Extent to which, according to the direct relatives, their autonomy was respected E4. Extent to which the direct relatives had the opportunity to be alone with their relative
F. Generic (in the care for relatives)	F1. Extent to which direct relatives received information that was understandable and unambiguous at the time of the patient's death F2. Extent to which direct relatives received information about the advantages and disadvantages of various types of treatment F3. Extent to which direct relatives perceived the expertise of caregivers and the continuity of care
G. Aftercare	G1. Extent to which direct relatives felt supported by the caregivers immediately after the patient's death G2. Extent to which direct relatives were informed about the possibilities of aftercare G3. Extent to which a final conversation or discussion was held to evaluate the care and the treatment