

Postprint Version	1.0
Journal website	http://pmj.sagepub.com/content/early/2014/09/02/0269216314546712.1.abstract
Pubmed link	http://www.ncbi.nlm.nih.gov/pubmed/25182656
DOI	10.1177/0269216314546712

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

Quality indicators for palliative care services: Mixed-method study testing for face validity, feasibility, discriminative power and usefulness

KATHLEEN LEEMANS¹ LUC DELIENS^{1,2} ANNEKE L FRANCKE^{2,3} ROBERT VANDER STICHELE^{1,4} LIEVE VAN DEN BLOCK^{1,5} JOACHIM COHEN¹

¹End-of-Life Care Research Group, Vrije Universiteit Brussel (VUB) & Ghent University, Brussels, Belgium

²Department of Public and Occupational Health, EMGO Institute for Health and Care Research, VU University Medical Centre, Amsterdam, The Netherlands

³Netherlands Institute for Health Services Research (NIVEL), Utrecht, The Netherlands

⁴Heymans Institute of Pharmacology, Ghent University, Ghent, Belgium

⁵Department of Family Medicine, Vrije Universiteit Brussel (VUB), Brussels, Belgium

ABSTRACT

Background: In the absence of a standardized, comprehensive and valid set of quality indicators for palliative care, we developed one for palliative care services in Belgium.

Aim: This study evaluates its face validity, feasibility, discriminative power and usefulness.

Design: We combined a quantitative analysis evaluating the answers with qualitative interviews with the contact persons of all participating services.

Setting: The quality indicator set was implemented in nine palliative care services in Belgium involving a measurement procedure with questionnaires to the patients of the services, their professional caregivers, family carers and physicians.

Results: The response rate was 56% for patients, 97% for caregivers, 56% for family carers and 65% for physicians, indicating good feasibility of the measurement procedure. During the interviews, caregivers found the indicator scores valid and none was extremely skewed, confirming their discriminative power. Still, 20 of the 80 indicators showed problems of feasibility and 5 of usefulness. One was discarded and the others were improved by changing either the formulation of the indicator or the questions used. Most participants expressed a desire for a smaller but still comprehensive set.

Conclusion: Based on the results, minor adjustments were made to individual indicators, to the measurement tools and to the procedure used; the quality

indicators are now ready for further evaluation and use across palliative care services in Belgium. As soon as these indicators are being used systematically, it will be possible to demonstrate and compare quality at the national and international levels and to evaluate improvement initiatives.

What is already known about the topic?

- Quality indicators for palliative care (Q-PAC) can be used by palliative care services to evaluate their practice and hence improve the care for the patients and their families.
- Although some Q-PAC have been developed, most indicator sets focus on specific populations such as cancer patients or on one dimension of care, mostly on physical aspects only.
- There is a need for a comprehensive indicator set comprising all the important dimensions of palliative care that can be used by the services for systematic evaluation and improvement of care.

What this paper adds?

- Using a mixed-method study, we tested a comprehensive quality indicator set that can allow palliative care services to monitor their service in a standardized and comprehensive manner.
- The set was evaluated by the palliative caregivers of the participating services as valid, useful and feasible in measuring and improving the quality of their care.

Implications for practice, theory and policy?

- This valid and comprehensive indicator set is ready to be implemented in all palliative care services in Belgium in order to enhance standardized evaluation of palliative care.
- Palliative care services using these indicators will be able to evaluate their care and improve it where needed.
- Researchers and policy makers need to evaluate further the optimal circumstances for comparison of quality between services.

INTRODUCTION

Measuring how well palliative care services are succeeding in delivering high-quality care requires systematic and continuous evaluation.¹⁻⁵ Although previous initiatives to develop quality monitoring tools have been described in the literature, most of them have developed patient-reported outcome measures meant to evaluate patient responses to treatment and not to evaluate and improve quality of care at the aggregate level of the service provider.^{1,6-10} To do so, quality indicators, that is, measurable aspects of care procuring improvement and transparency at aggregate level, need to be developed. In those projects that did develop quality indicators for palliative or end-of-life care, the focus is often on specific patient populations¹¹⁻¹⁹ or

on specific dimensions of palliative care such as physical aspects.^{20,21} Structure and process indicators were mostly developed;^{11,12,20-24} the more recent sets developed contain outcome indicators only.^{3,25} The Council of Europe has stated a need for quality indicators for palliative care (Q-PAC) that assess all relevant dimensions and hence reflect the multidisciplinary character of palliative care.²⁶

Therefore, in Belgium, we developed a comprehensive quality indicator set that can be used by palliative care services at home and in hospitals for systematic evaluation and improvement of care. Our indicator set differs from previously developed sets in that we aimed to provide a tool for internal monitoring of quality by assessing all important dimensions of palliative care and using structure, process and outcome indicators at the same time. Therefore, we developed a framework covering all important domains of palliative care (Table 1). We also took into account the perspectives of all the different stakeholders: patients, family, professional caregivers and policy makers. To clarify to the caregivers which dimensions of care they will be measuring, the set was divided into three separate thematic modules: (1) physical, psychosocial and spiritual aspects of care; (2) communication and care planning and (3) coordination of care.

[TABLE 1.]

We followed a scientifically rigorous method combining evidence and consensus (Figure 1), as suggested by Campbell et al.²⁷ for the development of quality indicators. This method led to an indicator set of 85 indicators with good content validity as judged by an expert panel.^{28,29} A systematic literature review on existing Q-PAC and an article on the development process of the indicators have been published elsewhere.^{20,30}

[FIGURE 1.]

Developing quality indicators is a first important step, but even if developed through a rigorous consensus method, they also have to be tested and evaluated in practice in terms of face validity, feasibility, discriminative power and usefulness before they can be implemented.^{19,27,29,31} Face validity can be defined as the extent to which an indicator is subjectively viewed as covering the concept it purports to evaluate.^{19,31} Feasibility mainly refers to the measurability of the quality indicators and the cost-benefit of the measurement procedure.^{19,31} Discriminative power looks at the capability of the indicator to discriminate between good and bad qualities.^{19,31} Usefulness concerns the extent to which results can be applied by palliative caregivers.^{19,31} The aim of this study was to test the developed quality indicators rigorously on a small scale in all types of palliative care services in Belgium by assessing their face validity, feasibility, discriminative power and usefulness and their measurement procedure in actual palliative care practice.

METHODS

Design

To evaluate the face validity, feasibility, discriminative power and usefulness of the quality indicators and the feasibility of the accompanying measurement procedure, we used a mixed-method design including a quantitative cross-sectional application of the quality indicators and qualitative interviews with caregivers using the indicator set.³⁰ Such a mixed-method design has been used before by Campbell et al.²⁷ to test quality indicators for general health care and by Claessen et al.³ to test indicators for palliative care.

Population and setting

In 2012, the indicator set was tested for feasibility among the four different types of palliative care services in Belgium: multidisciplinary palliative home care teams, palliative care units, multidisciplinary mobile palliative support teams in hospitals and palliative reference nurses in care homes. Multidisciplinary palliative home care teams support family physicians and community nurses in providing palliative care to patients at home. In hospitals, a multidisciplinary mobile palliative support team is at the disposal of any ward with patients with particular palliative care needs. Unlike the palliative care unit in a hospital, it is not a separate ward with its own beds. Care homes usually have a reference nurse who provides palliative care to residents in need.

Organizations were recruited on a voluntary basis via the Federation Palliative Care Flanders. We wanted at least two different services of each type taking into account regional variations. We chose the provinces with the lowest and highest percentages of home deaths within Flanders. In total, nine services participated over the two provinces:

- Two mobile home teams;
- Two palliative care units;
- Two mobile hospital teams;
- Three care homes for older people.

To measure all quality indicators, we cross-sectionally identified both patients who were living and those who had died 6 weeks to 6 months earlier, to limit the effects of automatic improvement of care over time. Selected patients had to meet the following inclusion criteria:

- To be receiving support from the palliative care service
 - For care homes: having a palliative care record or receiving comfort care;
 - For palliative home care teams: at least one face-to-face contact additional to the telephonic application;
- To be at least 18 years old.

Questionnaires used to measure the quality indicators

To be able to calculate the performance scores of the indicators with a nominator and a denominator, information was gathered via five different questionnaires.

1. For the patients receiving care from the service, containing questions about the process and outcome of care.
2. For the main professional caregivers of those patients (nurse, physician or psychologist of the team), containing questions about the process and outcome of care; to be completed while a patient is alive.
3. For family carers of patients who had died 6 weeks to 6 months before the measurement, about the last weeks before death and the support for family carers.
4. For professional caregivers of those patients (nurse, physician or psychologist of the team) containing questions about the last weeks before death.
5. For the palliative care services containing structural aspects that had to be completed only once.³⁰

All questionnaires were pre-tested in the target group (i.e. palliative patients, professional caregivers and family carers) for comprehensibility and response burden; they were also discussed in an expert panel meeting in order to establish face and content validity. Recommendations from the experts and the target group resulted in minor changes in the questionnaires for family carers.

Procedure

At the beginning of the feasibility study, a contact person was appointed from every service, responsible for supervision and communication within the service and distribution of the questionnaires during the whole study (Figure 2). This person first selected both eligible groups of patients (those under care and those deceased between 6 weeks and 6 months previously) using a separate checklist listing all necessary contact details and socio-demographic characteristics. Then, they distributed all questionnaires to the four different respondents and completed the service questionnaire. Finally, one reminder was sent to non-responding patients and family carers and up to two to professional caregivers. Throughout the mailing procedure, a manual explaining the procedure and operation of the quality indicator set was available.

[FIGURE 2.]

Before the start of the study, the cross-sectional measurement procedure was fine-tuned by an expert panel consisting of different stakeholders in palliative care (care providers, care users and policy makers) taking into account feasibility and workload.

We chose not to present the performance scores in this article because the data cannot be generalized and might be wrongly interpreted, because of the preliminary status of the use of the quality indicator set.

Qualitative evaluation

After the data collection, the performance scores of the quality indicators were individually fed back to the participating services. An evaluative interview using an interview guide was held with each contact person in terms of workload, feasibility, usefulness of the indicators and their results and future use of the quality indicators.

Measurements

Descriptive and psychometric analysis (in SPSS version 21.0) was used to evaluate feasibility and discriminative power. The qualitative interviews and open questions at the end of each patient's and family carer's questionnaire were used to evaluate face validity, feasibility and usefulness. The measurement procedure was evaluated for feasibility. An overview of all evaluation aspects is presented in Table 2.

[TABLE 2.]

Ethics

At inclusion, all respondents received a questionnaire and a covering letter signed by the coordinator of the service providing information about the purpose and the voluntary character of the study. Because the services were responsible for the distribution of the questionnaires and anonymous numbers were used for each participant, the completed questionnaires received by the researchers could never be linked to the identifying information and anonymity was preserved at all time. Informed consent of all patients, family members and caregivers was received. The protocol of the whole study was approved by the Ethical Review Board of Brussels University Hospital of the Vrije Universiteit Brussel (14320112708).

RESULTS

During the feasibility study, 116 patients, 121 professional caregivers, 193 family carers and 192 physicians from all nine palliative care services met the inclusion criteria and received a questionnaire (Table 3). The net response rate was 56% ($n = 64$) for patients, 97% for caregivers ($n = 117$), 56% for family carers ($n = 108$) and 65% for physicians ($n = 125$). Based on these response rates, the feasibility of the measurement procedure can be evaluated as positive.

[TABLE 3.]

Moreover, during the interviews, all contact persons except the ones from the palliative support teams in hospitals said they would use the instrument again in the future. To facilitate feasibility, they would prefer a shorter but still comprehensive version of the indicator set (i.e. a minimal set) if available. All contact persons declared that the time invested in the study was worthwhile. Only 9 of the 116 participating patients and 1 of the family carers found that the time required to complete the whole questionnaire was too much. Furthermore, they all evaluated the manual and checklists as clear and useful.

In terms of face validity, the contact persons confirmed during the interviews that the quality indicators appear to measure the relevant quality and that the results appeared to reflect their practice and hence seemed valid. Even so, 20 indicators showed problems with feasibility, that is, too many missing answers (these are indicated in Tables 4–6). There were no indicators with an extremely skewed distribution, that is, the indicators showed good discriminative power. Furthermore, the contact persons agreed the results were useful in terms of improving their service. Only five indicators showed problems with usefulness, that is, results were not evaluated as useful for quality improvement within the services.

[TABLE 4.][TABLE 5.][TABLE 6.]

Overview of all quality indicator titles in the coordination of care and circumstances surrounding death module of the Q-PAC set (translated from Dutch).

Decisions and adjustments based on the results of the feasibility study

During the qualitative interviews, some adjustments in the measurement procedure were suggested by the contact persons. For example, the patient questionnaires should be handed over in person, making it possible to add some explanation, to answer questions and to assure them that participation is voluntary and would not affect their care.

The 25 indicators that showed problems in terms of feasibility and usefulness were dealt with either by changing the formulation of the indicator or the questions used to measure the indicator or by discarding the indicator from the set. One of them was discarded, that is, ‘number of patients assessed for pain within 48 h after the start of palliative care’ because most caregivers could not answer the question regarding the time frame of the pain assessment. On top of that, the indicator ‘number of patient assessed for pain’ measures the same quantity, albeit without the time frame. Table 7 shows three examples of how we changed or improved the indicators based on the results of the feasibility study.

[TABLE 7.]

The final Q-PAC quality indicator set now consists of 84 indicators in three modules. In this article, we only present the indicator titles per module in Tables 4–6. Changes as compared with the original indicators are described in the footnote of the tables. A list of all indicators described in more detail (including numerators, denominators and questions) is available from the authors upon request (translated from Dutch to English).

DISCUSSION

In this study, we evaluated a quality indicator set designed to measure the quality of care delivered by palliative care services in Belgium. Caregivers in the palliative care services confirmed the face validity of the indicator set, that is, that it covers the

aspect that it purports to evaluate; response rates from patients, family carers and professional caregivers were high and the measurement procedure was evaluated as feasible by the caregivers, hence the developed quality indicators were found to be valid, feasible, discriminative and useful. This implies that the Q-PAC quality indicators are ready to be used in palliative care services in Belgium in order to further validate and implement the indicators and at long last to monitor the quality of palliative care for patients and their families.

One of the limitations of our feasibility study is that it is limited by the limited sample of palliative care services; therefore, the results in terms of feasibility cannot necessarily be generalized. However, with similar working across services within each type, we expect the results to be transferable to all services in Belgium. This needs to be further evaluated in a larger population of palliative care providers to confirm generalizability of results. Although response rate was high, some form of response bias with an important impact on the measurement cannot be fully excluded.

An important strength of the study is the mixed-method design including quantitative analysis of data and qualitative interviews with all participants in combination with a small sample of services. Hence, we could thoroughly evaluate the indicator set and its measurement procedure in terms of face validity, feasibility, discriminative power and usefulness. Our close follow-up of the process in every service allowed us to see clearly all barriers and facilitators influencing the course of the measurement. These factors were also explored during the evaluative interviews with the services and are used in the current implementation research using focus group interviews to explore them further.³² Based on these barriers and facilitators, implementation strategies and an implementation plan will be developed that can be used as a guide for researchers as well as participating services.

Our study resulted in some adjustments to the individual quality indicators, and it also indicated the need to modify the measurement procedure based on the factors that influence the measurements. Although most services were positive and said they would use the indicators in the future, there were some problems with the palliative support teams in hospitals. Few patients were eligible for inclusion while they were still alive, and fewer family carers returned a completed questionnaire than did participants from the other services. One explanation could be that because the mobile support teams function as a support for the treating physicians on several hospital wards, family carers were not always aware of what they did and sometimes did not know that the patient had been seen by them. Additionally, mobile palliative support teams in hospitals often chose not to deliver a questionnaire to eligible patients or their proxies because they considered it would be a psychological burden to them. The number of patients currently receiving support was also relatively small in the individual support teams, care homes and, to a lesser extent, in the palliative care units in hospitals. A larger number would be needed for monitoring within one specific service, preferably at least 10 patients per service. We therefore propose an additional inclusion period for patients under guidance of the service order to increase the numbers and hence the reliability of the results. Further decisions on

adjusting the measurement procedure will be made together with some experts in the field.

In the future, palliative care services will be invited to work voluntarily with the quality indicators to monitor their practice, the intention being that voluntary rather than obligatory use of the indicators will mean that caregivers will apply the quality information in a more considered manner. They will be recommended to measure quality indicators twice a year in order to see what aspects of care are going well and which need improvement. However, our qualitative evaluation in conjunction with the users showed that they would prefer a more limited but still comprehensive set of quality indicators rather than the whole set. Such a minimal set should incorporate core indicators over the three modules, with optional thematic modules that they can choose to measure alternately to evaluate aspects of their functioning. This would reduce the length of the questionnaires for all respondents and the workload for the caregivers and should lead to more palliative care services being willing to measure quality indicators leading to systematic monitoring on a national level.

CONCLUSION

Our study indicates the good face validity, feasibility, discriminative power and usefulness of a set of Q-PAC services in Belgium. With some minor adjustments to the quality indicators and measurement procedures, our quality indicators can be used across all types of palliative care services in Belgium. Before doing so, the indicator set can best be reduced to a minimal set with optional thematic modules to reduce the length of the questionnaires and workload. After implementation, further validation of the indicators will be needed, and discriminative power over time, as well as best practice norms, can be defined in order to develop continuous improvement in the quality of palliative care. The indicator set and the measurement procedure can even be of use to palliative care services in other countries. This would create more standardization of quality evaluation across palliative care services and could eventually provide benchmarking information at the national and international levels. However, adequate feasibility testing, taking into account regional organizational specificities, is recommended. Our article presents a methodological basis for such testing.

Acknowledgments

We thank the Flemish Federation of Palliative Care for their support in the project. We also thank the participating services and their contact persons for their time and excellent work. We thank Jane Ruthven for her language editing. The full indicator set for palliative care in Flanders is available upon request from the authors. This study is part of the 'Flanders Study to Improve End-of-Life Care and Evaluation Tools (FLIECE-project)', a collaboration between the Vrije Universiteit Brussel, Ghent University, the Katholieke Universiteit Leuven, Belgium, and VU University Medical Centre Amsterdam, The Netherlands. Joachim Cohen and Lieve Van den Block are postdoctoral fellows of the Research Foundation Flanders.

ARTICLE NOTES

- Declaration of conflicting interests The authors declare that there is no conflict of interest.
- Funding This study was supported by a grant from the Flemish Government Agency for Innovation by Science and Technology (agentschap voor Innovatie door Wetenschap en Technologie) (SBO IWT no. 100036).

REFERENCES

1. Bausewein C, Daveson BA, Benalia H, et al. Outcome measurement in palliative care: the essentials. London: King's College, 23 March 2011, <http://www.csi.kcl.ac.uk/files/Guidance%20on%20Outcome%20Measurement%20in%20Palliative%20Care.pdf>
2. Bowman KW, Martin DK, Singer PA. Quality end-of-life care. *J Eval Clin Pract* 2000; 6(1): 51–61.
3. Claessen SJ, Francke AL, Belarbi HE, et al. A new set of quality indicators for palliative care: process and results of the development trajectory. *J Pain Symptom Manage* 2011; 42(2): 169–182.
4. Dy SM, Lupu D, Seow H. Progress towards systems of quality measurement that capture the essence of good palliative care. *Palliat Med* 2012; 26(4): 291–293.
5. Higginson IJ. Evidence based palliative care. There is some evidence – and there needs to be more. *BMJ* 1999; 319(7208): 462–463.
6. Bausewein C, Simon ST, Benalia H, et al. Implementing patient reported outcome measures (PROMs) in palliative care – users' cry for help. *Health Qual Life Outcomes* 2011; 9: 27.
7. Eagar K, Watters P, Currow DC, et al. The Australian Palliative Care Outcomes Collaboration (PCOC) – measuring the quality and outcomes of palliative care on a routine basis. *Aust Health Rev* 2010; 34(2): 186–192.
8. Lundstrom S, Axelsson B, Heedman PA, et al. Developing a national quality register in end-of-life care: the Swedish experience. *Palliat Med* 2012; 26(4): 313–321.
9. Martinsson L, Furst CJ, Lundstrom S, et al. Registration in a quality register: a method to improve end-of-life care – a cross-sectional study. *BMJ Open* 2012; 2(4): e001328.
10. Department of Health. End of life care strategy: quality markers and measures for end of life care. UK: Crown Publishing, 2009.
11. 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.
12. 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(17): 3820–3829.
13. De Vos ML, Van der Veer SN, Graafmans WC, et al. Implementing quality indicators in intensive care units: exploring barriers to and facilitators of behaviour change. *Implement Sci* 2010; 5: 52.
14. Dy SM, Lorenz KA, O'Neill SM, et al. Cancer Quality-ASSIST supportive oncology quality indicator set: feasibility, reliability, and validity testing. *Cancer* 2010; 116(13): 3267–3275.
15. 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(6): 505–509.
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): S318–S326.
17. Miyashita M, Nakamura A, Morita T, et al. Identification of quality indicators of end-of-life cancer care from medical chart review using a modified Delphi method in Japan. *Am J Hosp Palliat Care* 2008; 25(1): 33–38.
18. Miyashita M, Morita T, Ichikawa T, et al. Quality indicators of end-of-life cancer care from the bereaved family members' perspective in Japan. *J Pain Symptom Manage* 2009; 37(6): 1019–1026.
19. Wennekes L. Development and validation of quality indicators for cancer care. Nijmegen, The Netherlands: Radboud University Nijmegen Medical Centre, 2013.

20. De Roo ML, Leemans K, Claessen SJ, et al. Quality indicators for palliative care: update of a systematic review. *J Pain Symptom Manage* 2013; 46(4): 556–572.
21. Pasman HR, Brandt HE, Deliens L, et al. Quality indicators for palliative care: a systematic review. *J Pain Symptom Manage* 2009; 38(1): 145–156.
22. 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.
23. Sato K, Miyashita M, Morita T, et al. Reliability assessment and findings of a newly developed quality measurement instrument: quality indicators of end-of-life cancer care from medical chart review at a Japanese regional cancer center. *J Palliat Med* 2008; 11(5): 729–737.
24. Woitha K, Van BK, Ahmed N, et al. Development of a set of process and structure indicators for palliative care: the Europall project. *BMC Health Serv Res* 2012; 12: 381.
25. 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(7): 859–868.
26. Palliative care: a model for innovative health and social policies, 1649. Council of Europe, 2009, <http://www.sicp.it/materiali/palliative-care-model-innovative-health-and-social-policies-resolution-1649>
27. Campbell SM, Kontopantelis E, Hannon K, et al. Framework and indicator testing protocol for developing and piloting quality indicators for the UK quality and outcomes framework. *BMC Fam Pract* 2011; 12: 85.
28. Campbell SM, Braspenning J, Hutchinson A, et al. Research methods used in developing and applying quality indicators in primary care. *BMJ* 2003; 326(7393): 816–819.
29. druk vierde herziene Grol R, Wensing M. Implementatie: effectieve verbetering van de patiëntenzorg (ed drukvierde herziene). Amsterdam: Reed Business, 2011.
30. Leemans K, Cohen J, Francke AL, et al. Towards a standardized method of developing quality indicators for palliative care: protocol of the Quality Indicators for Palliative Care (Q-PAC) study. *BMC Palliat Care* 2013; 12(1): 6.
31. Claessen SJJ. New developments in palliative care: quality indicators and the palliative care continuum. Ede: GVO drukkers & vormgevers B.V./Ponsen & Looijen, 2012.
32. Grol R, Wensing M. What drives change? Barriers to and incentives for achieving evidence-based practice. *Med J Aust* 2004; 180(6 Suppl.): S57–S60.

TABLES AND FIGURES

Table I. Representation of the nine quality domains in the indicator set.

Domain of quality palliative care	No. of QI
1. Physical treatment and care	12
2. Psychological, social and existential treatment and care	16
3. Information, communication, planning and decision making with patients	20
4. Information, communication, planning and decision making with family	6
5. Information, communication, planning and decision making with other caregivers	3
6. Type of care at the end of life	6
7. Coordination and continuity of care	9
8. Support of family and informal caregivers	9
9. Structure of care	4
Total no. of QI	85

QI: quality indicator.

QI development method	Level of comprehensiveness
1. Systematic literature review <i>Which quality indicators already exist?</i>	Quality indicators for all palliative patients in all palliative care services
2. Framework <i>Which domains of PC need to be measured?</i>	Structure Process of palliative care Outcome
3. RAND/UCLA expert panel <i>Which indicators are appropriate for quality measurement in PC?</i>	Involvement of all stakeholders: Caregivers, patient and family perspective, administrators

Figure I. Standardized method for comprehensive quality indicator development in palliative care.

PC: palliative care. RAND/UCLA: Research ANd Development corporation in collaboration with the University of California at Los Angeles

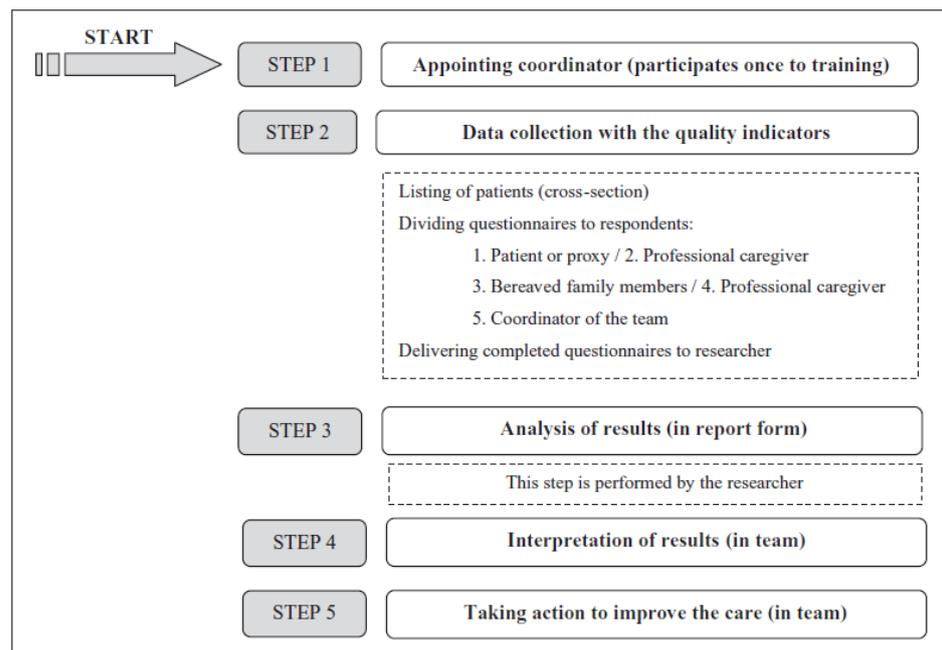


Figure 2. Schematic representation of measurement procedure of the quality indicators for palliative care.

Table 2. Definitions, sources, evaluation methods and judgment criteria of the evaluation aspects.

Aspect	Definition	Source	Evaluation method	Criterion to judge aspect as adequate
Individual quality indicators				
Face validity	The extent to which the indicator set is subjectively viewed as covering the concept it purports to measure	Qualitative	During interview, participants were asked whether they felt the indicators measured the quality of the care delivered by the service	Subjective confirmation from the contact persons
Feasibility	The extent to which the quality indicators are measurable	Quantitative	Psychometric analyses of missing values	Not more than 10% missing values for an indicator
Discriminative power	The extent to which a quality indicator discriminates between good and bad qualities	Quantitative	Psychometric analysis of skewness/distribution	Not more than 95% of answers in an extreme category
Usefulness	The extent to which the scores of the quality indicators can be used to improve the care	Qualitative	During the interview, participants were asked whether they could use the scores of the indicators to interpret the quality of care and if they could identify domains in need of improvement	Subjective confirmation by the contact person
Overall quality indicators' measurement				
Feasibility	The extent to which the measurement procedure is cost-benefit efficient	Quantitative	Response percentage	More than 50%
		Qualitative	Workload for contact person during testing period	Subjective opinion of the contact person
		Qualitative	Question in the questionnaire: 'How did you feel about the length of the questionnaire?'	Subjective opinion of the respondents

Table 3. Number included (participating) in the feasibility study.

Service	Living patients		Deceased patients	
	Patients ^{a,b}	Caregivers ^c	Family carers	Physicians ^d
Two mobile home teams	74 (38)	75 (74)	73 (39)	72 (49)
Two palliative care units in a hospital	12 (8)	13 (12)	66 (39)	66 (51)
Two mobile teams in a hospital	7 (3)	10 (10)	19 (7)	19 (18)
Three care homes for the elderly	23 (15)	23 (21)	35 (23)	35 (24)
Total	116 (64)	121 (117)	193 (108)	192 (125)

Presented numbers are the number of included respondents and between parentheses the actual participants.

^aWhen patients were cognitively or physically not able to complete a questionnaire, a family member was assigned as proxy to complete the questionnaire for (or together with) the patient.

^bIn total, 13 patients were excluded from the study: 8 died before receiving the questionnaire, 3 questionnaires were withheld by the caregivers because of burdensome for the patient at that moment, 1 questionnaire returned by mail and 1 questionnaire was completed inaccurately and therefore unusable.

^cEight caregivers were excluded from the study: questionnaires were lost in mail.

^dOne physician was excluded from the study: not the treating physician of the deceased patient.

Table 4. Overview of all quality indicator titles in the bio–psycho–social–spiritual module of the Q-PAC set after evaluation and adjustment based on the results of the feasibility study (translated from Dutch).

	Rater	Indicator title
1	Ca	Percentage of patients who were subjected to a general symptom assessment on a validated scale
2	Ph	Percentage of patients whose symptom burden was mostly or completely under control in the final week of life
3	Ca	Percentage of patients who were subjected to a pain assessment, with or without pain scale
4	Ca	Percentage of patients who were subjected to a delirium assessment, with or without delirium scale
5	Ca	Percentage of patients who were subjected to an anxiety assessment, with or without anxiety scale
6	Pa	Percentage of patients who were most of the time or always treated for pain
7	Pa	Percentage of patients who were most of the time or always guided for anxiety
8	Ca	Percentage of patients treated for delirium
9	Pa	Percentage of patients who, after treatment, experienced significant improvement in pain
10	Pa	Percentage of patients who, after treatment, experienced significant improvement in anxiety ^a
11	Ca	Percentage of patients for whom the delirium improved substantially or completely after the treatment
12	Fc	Percentage of patients for whom the delirium improved sufficiently after the treatment (family carers)
13	Ca	Percentage of patients whose shortness of breath was relieved within 48 h after admission or starting palliative care ^b
14	Pa	Percentage of patients with a score of 3 or less on a scale of 0–10 (average over 3 days) for pain
15	Pa	Percentage of patients with a score of 3 or less on a scale of 0–10 (average over 3 days) for anxiety
16	Fc	Percentage of family carers who indicated that caregivers were most of the time or always attentive to their anxiety and despondency
17	Pa	Percentage of patients who indicated that the caregivers were most of the time or always attentive to their personal situation and needs
18	Pa	Percentage of patients who indicated that the caregivers regularly assessed how they were feeling
19	Pa	Percentage of patients who indicated that the caregivers regularly talked to them about spirituality and religion in an understanding way ^c
20	Fc	Percentage of family carers who indicated that the caregivers regularly talked to them about what it meant to them to care for their ill next of kin
21	Fc	Percentage of family carers who indicated that the caregivers regularly asked how they were feeling
22	Fc	Percentage of family carers who indicated that the caregivers regularly talked to them about spirituality and religion in an understanding way ^c
23	Pa	Percentage of patients with a score of 5 or more on a scale of 0–10 for psychological well-being ^d
24	Pa	Percentage of patients with a score of 5 or more on a scale of 0–10 for social well-being ^d
25	Pa	Percentage of patients with a score of 5 or more on a scale of 0–10 for spiritual well-being ^d
26	Pa	Percentage of patients with a score of 5 or more on a scale of 0–10 for quality of life ^d
27	Pa	Percentage of patients who were most of the times or always offered counselling when they were not feeling well or feeling less well
28	Fc	Percentage of family carers who were most of the time or always offered counselling when they were not feeling well or feeling less well
29	Pa	Percentage of patients who indicated that they could most of the time or always be alone and talk to someone undisturbed if wanted
30	Pa	Percentage of patients who indicated that the caregivers most of the times or always respected their personal wishes and that they could most of the time or always plan their day and decide about the care provided
31	Pa	Percentage of patients who were most of the time or always able to have some privacy with their family carers if wanted
32	Pa	Percentage of patients who indicated that most or all of their caregivers respected their philosophy of life
33	Fc	Percentage of family carers who indicated that most or all of the caregivers respected their philosophy of life
34	Pa	Percentage of patients who indicated that a priest or spiritual counsellor was available ^a

Q-PAC: quality indicators for palliative care; Pa: patient; Ca: caregiver; Fc: family carer; Ph: physician.

^aThis indicator showed problems with feasibility (too much missing answers) when measured with proxies. The question used to measure the indicator was changed by adding an 'I don't know' answering category in the questionnaire of the proxy.

^bThis indicator showed problems with feasibility (too many missing answers). We added an 'I don't know' and a 'not applicable' answering category to the questions used to measure the indicator.

^cThese indicators showed problems with feasibility (too many missing answers). We combined the three original questions into one clear question covering all components of the indicator in order to minimize the number of missing answers.

^dThese indicator showed problems with feasibility (too many missing answers) when measured with proxies. As they are measured by validated questions from the McGill Quality of Life Questionnaire and did not show problems when measured with patients, the authors decided to keep the indicators in their original form.

Table 5. Overview of all quality indicator titles in the communication and care planning module of the Q-PAC set after evaluation and adjustment based on the results of the feasibility study (translated from Dutch).

	Rater	Indicator title
1	Pa	Percentage of patients who received the right amount of information about their diagnosis ^a
2	Pa	Percentage of patients who received the right amount of information about their prognosis ^a
3	Pa	Percentage of patients who received the right amount of information about the course of the disease ^a
4	Pa	Percentage of patients who received the right amount of information on the advantages and disadvantages of treatments ^a
5	Pa	Percentage of patients who received the right amount of information on palliative care options ^a
6	Fc	Percentage of family carers who received sufficient information about palliative lump sum and palliative leave
7	Fc	Percentage of family carers who received the right amount of information about the patient's condition and treatments
8	Fc	Percentage of family carers who received the right amount of information about the patient's approaching death
9	Fc	Percentage of patients who received the right amount of information about the treatment or end-of-life decision they requested
10	Fc	Percentage of patients (or family carers in case the patient lacked capacity) who were sufficiently informed when a treatment or end-of-life decision was taken ^b
11	Pa	Percentage of patients who indicated that they most of the time or always received clear and comprehensible and never or sometimes contradictory information
12	Fc	Percentage of family carers who received clear and comprehensible and non-contradictory information about the patient's approaching death
13	Pa	Percentage of patients who indicated that they discussed their wishes about care objectives with a physician (to patient) ^a
14	Ph	Percentage of patients with whom the physician discussed the care objectives (to physician)
15	Ca	Percentage of patients about whom multidisciplinary consultations took place at least once a week about their care objectives
16	Ca	Percentage of patients whose family physician was regularly or always involved in these multidisciplinary consultations ^c
17	Ca	Percentage of patients about whom a conversation about their care preferences took place between the caregivers and family carers in the first week after admission or start of palliative care
18	Fc	Percentage of patients whose authorized representative was involved when the patient lost capacity
19	Pa	Percentage of patients who are not receiving treatments they do not want ^a
20	Pa	Percentage of patients who are not receiving drugs they do not want ^a
21	Ph	Percentage of patients who were not started on artificial fluids and/or nutrition in the last month before death
22	Fc	Percentage of patients for whom starting or terminating administration of artificial fluids and/or nutrition was discussed with family carers
23	Ca	Percentage of patients whose wishes on resuscitation (DNR code) are known to the caregivers ^c
24	Ca	Percentage of patients who were asked how they felt about end-of-life decisions and euthanasia
25	Fc	Percentage of patients who got a positive response to (all) their request(s) for a treatment or an end-of-life decision
26	Fc	Percentage of patients who were involved in the final treatment or end-of-life decision (after a request by the patient)
27	Fc	Percentage of patients (or family carers in case the patient lacked capacity) who were involved in the treatment or end-of-life decision (without a request by the patient) ^b

Q-PAC: quality indicators for palliative care; Pa: patient; Ca: caregiver; Fc: family carer; Ph: physician; DNR: do not resuscitate.

^aThese indicators showed problems with feasibility (too many missing answers) when measured with proxies. The questions used to measure the indicators were changed by adding an 'I don't know' answering category in the questionnaire of the proxy.

^bThese indicators showed problems with feasibility (too many missing answers). Because they can only be measured with family carers, the authors therefore decided to add an 'I don't know' answering category to the questions used to measure them.

^cThese indicators showed problems with usefulness. In the qualitative interviews, not all contact persons found the indicators distinctly for their practice. According to the authors, they measure important aspects of care for every service, and not every service does necessarily have to score high on the indicator. Therefore, the indicators were kept in their original forms.

Table 6. Overview of all quality indicator titles in the coordination of care and circumstances surrounding death module of the Q-PAC set (translated from Dutch).

	Rater	Indicator title
1	Ph	Percentage of patients who were not started on a new course of chemotherapy after admission or start of palliative care ^a
2	Ph	Percentage of patients whose palliative care started at least 2 weeks before death
3	Ph	Percentage of patients admitted more than once to the emergency room since admission or start of palliative care ^a
4	Ph	Percentage of patients admitted to the intensive care unit since admission or start of palliative care ^a
5	Pa	Percentage of patients who were most of the time or always able to have some privacy with their family carers if wanted
6	Fc and Ph	Percentage of patients who scored 5 or more on a scale of 0–10 for the quality of death (according to family carers and physicians)
7	Fc	Percentage of family carers who felt they had adequate support after the patient's death (inclusive evaluation meeting) and were informed of the possibilities of after-care
8	Fc	Percentage of family carers who were given as much assistance and training as necessary for practical issues and had someone available for help with these issues
9	Fc	Percentage of family carers who were given as much assistance as necessary with the care process
10	Fc	Percentage of family carers who were most of the time or always able to have some privacy with the patient if wanted
11	Ca	Percentage of patients whose family physician, home nurse and physiotherapist (when available) were involved in the care
12	Ph	Percentage of patients who were in touch with their family physician on a weekly basis in the last 3 months before death (personally or by telephone)
13	Ca	Percentage of patients whose caregivers were given information about care and treatment prior to admission or starting palliative care
14	Ca	Percentage of patients whose caregivers were given a summary of the patient's medical records during the admission or after starting palliative care
15	Ca	Percentage of patients whose caregivers were given the care objectives and resuscitation status during or after admission or starting palliative care
16	Ca	Percentage of patients for whom the prognosis, psychosocial symptoms, functional status, symptom burden and documentation about care wishes were entered in the file within 48 h after admission or starting palliative care
17	Pa	Percentage of patients who believed that their caregivers were sufficiently informed of their medical care history to be able to provide the best possible care
18	Pa	Percentage of patients who most of the time or always felt they were given continuous care by their various caregivers
19	Pa	Percentage of patients who mostly or entirely knew who to talk to about their care
20	Se	Percentage of services that have a guideline on requests for euthanasia
21	Se	Percentage of services that have a 'care for the carer' policy
22	Se	Percentage of services with a policy allowing unlimited visits of family carers and friends to terminal patients
23	Se	Percentage of services offering comfortable accommodation to the patient's family carers

Q-PAC: quality indicators for palliative care; Pa: patient; Ca: caregiver; Fc: family carer; Ph: physician; Se: service.

^aThese indicators, origin of Earle et al.,¹⁵ were measured 'in the last 30 days of life'. In this form, the indicators showed problems with usefulness: they did not measure the quality of care provided by the service. Therefore, 'in the last 30 days of life' was replaced by 'since admission or start of palliative care'.

Table 7. Three examples of quality indicators that were adjusted after being evaluated as problematic during the feasibility study.

Example 1: Percentage of patients for whom a priest or spiritual counsellor is available (bio-psycho-social-spiritual module)

Numerator	Number of patients for whom a priest or spiritual counsellor is available
Denominator	Total number of patients for whom this indicator was measured
Question	Is there a spiritual or moral consultant available for you to consult? (patient) <input type="checkbox"/> Yes <input type="checkbox"/> No
Evaluation	Problems with feasibility: 15% of patients did not answer the question
Adjustment	We changed the answering categories: Is there a spiritual or moral consultant available for you to consult? <input type="checkbox"/> Yes, available <input type="checkbox"/> Yes, but I don't need to consult him <input type="checkbox"/> No, not available

Example 2: Percentage of patients for whom the family physician was involved in the multidisciplinary meetings (communication and care planning module)

Numerator	Number of patients for whom the family physician often or every time was involved in the multidisciplinary meeting
Denominator	Total number of patients for whom the indicator was measured
Question	Was the family physician involved at these multidisciplinary meetings? (caregiver) <input type="checkbox"/> Yes, every time <input type="checkbox"/> Yes, often <input type="checkbox"/> Yes, sometimes <input type="checkbox"/> No, never
Evaluation	Problems with usefulness: the contact persons of the palliative care units and mobile support teams (hospital) did not find this indicator useful for their service
Adjustment	We decided to keep the indicator in its original form for all services because of its importance. Palliative care units and palliative support teams will score lower on this indicator than the other services, but that will be compensated by taking into account case mix adjusters and by setting the right norms for these types of services.

Example 3: Percentage of patients for whom no new course of chemotherapy was started in the last month of life (coordination and circumstances surrounding death module)

Numerator	Number of patients for whom no new course of chemotherapy was started in the last month of life
Denominator	Total number of cancer patients
Question	When was this patient for the last time started on a new course of chemotherapy? (physician) <input type="checkbox"/> (mm/dd/yyyy) <input type="checkbox"/> I don't know <input type="checkbox"/> Not applicable
Evaluation	Problems with usefulness: this indicator does not measure the quality of care provided by the service
Adjustment	We changed the indicator title and numerator so that the indicator measures the quality of care provided by the service: Title: Percentage of patients for whom no new course of chemotherapy was started <i>since the start of palliative care</i> Numerator: Number of patients for whom no new course of chemotherapy was started <i>since the start of palliative care</i>