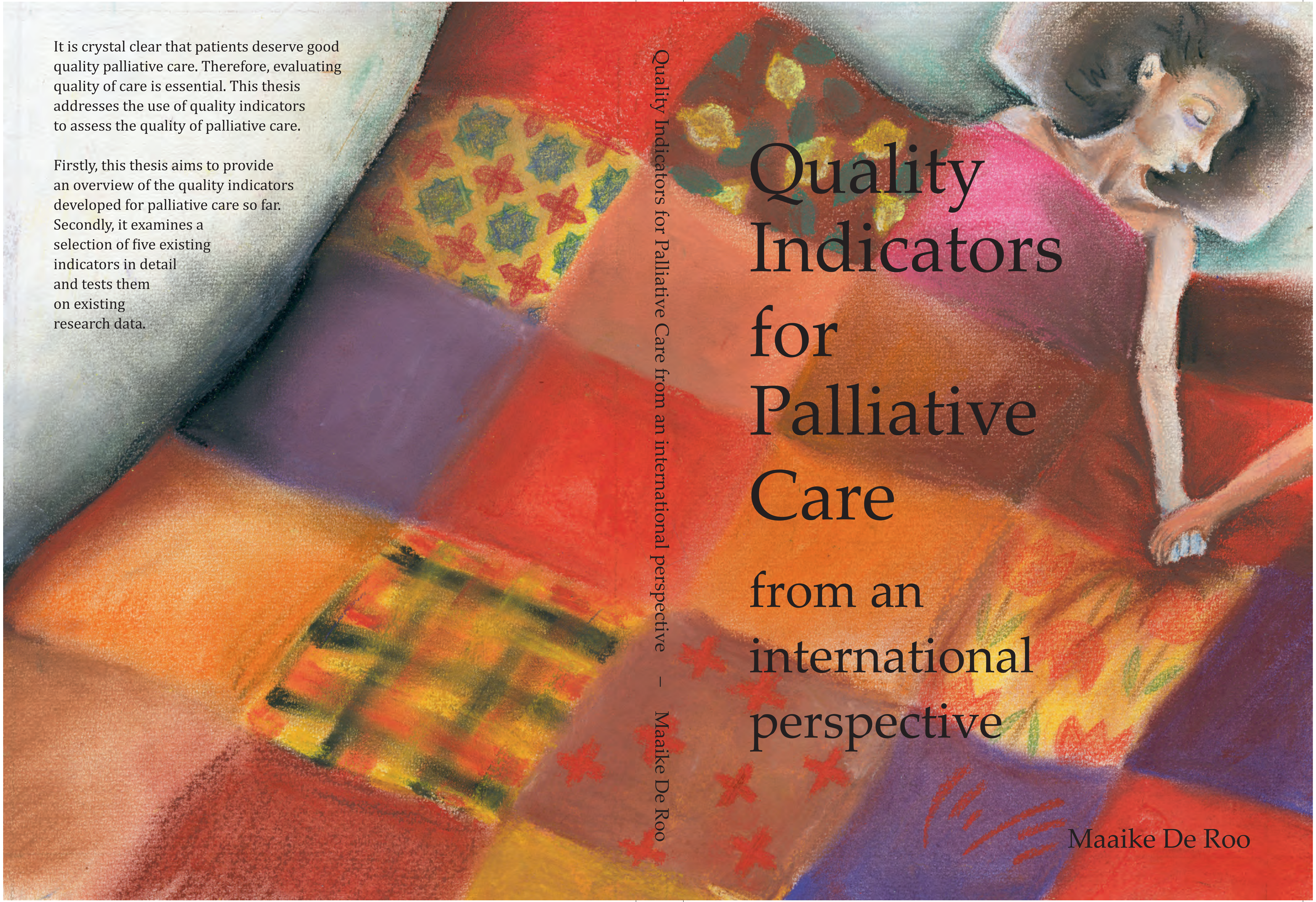

It is crystal clear that patients deserve good quality palliative care. Therefore, evaluating quality of care is essential. This thesis addresses the use of quality indicators to assess the quality of palliative care.

Firstly, this thesis aims to provide an overview of the quality indicators developed for palliative care so far. Secondly, it examines a selection of five existing indicators in detail and tests them on existing research data.

Quality Indicators for Palliative Care from an international perspective – Maaike De Roo

# Quality Indicators for Palliative Care

## from an international perspective

Maaike De Roo

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**UITNODIGING**

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de openbare verdediging
van het proefschrift

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for Palliative Care
from an international
perspective**

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op de receptie

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# Quality Indicators for Palliative Care

## from an international perspective

Maaike De Roo

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# Quality Indicators for Palliative Care from an international perspective

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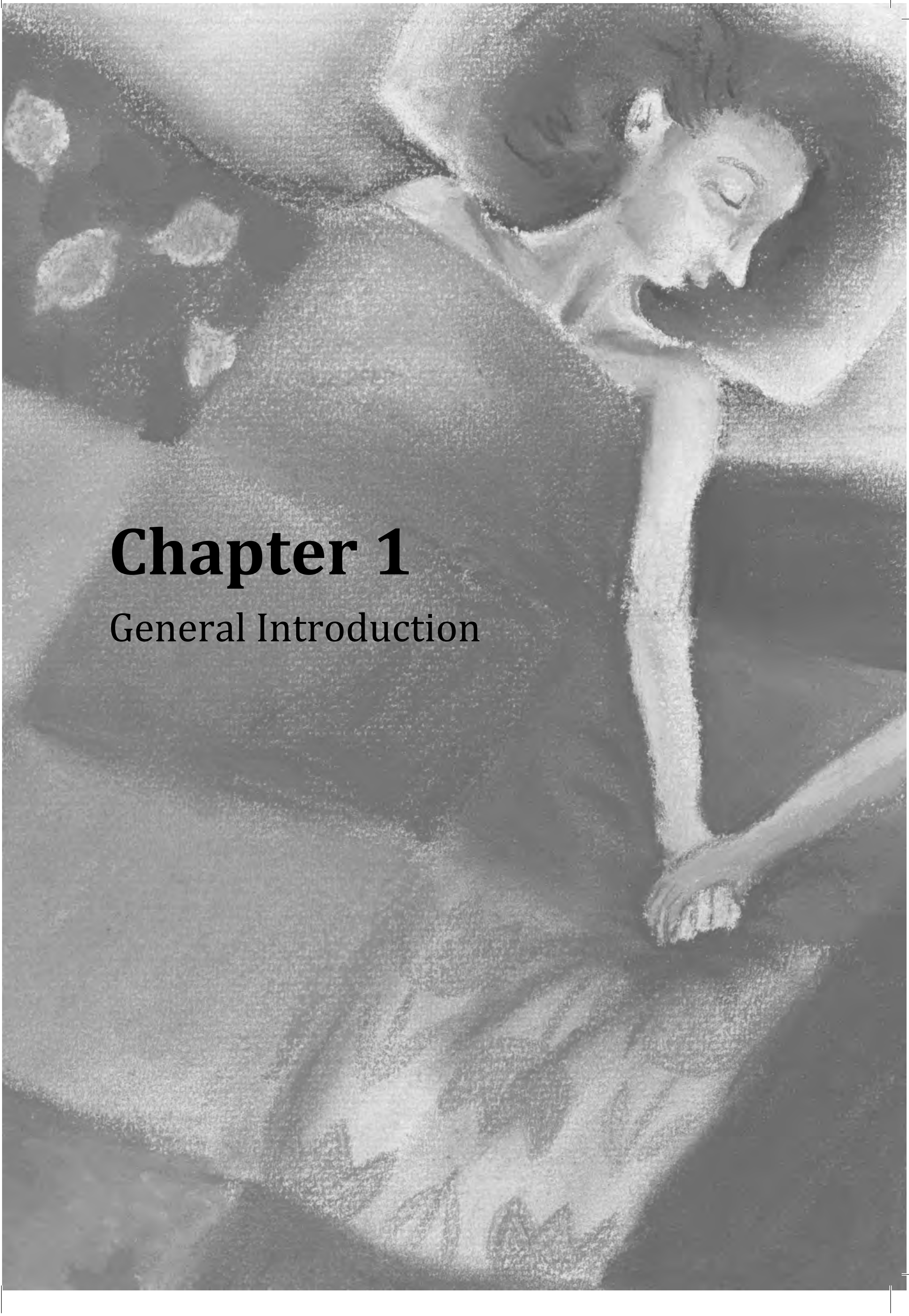
## CONTENTS

# Chapter 1

## General Introduction



This thesis focuses on quality indicators that can be used to assess and subsequently improve the quality of palliative care, from an international point of view. This introduction will first provide some insights into what palliative care is and how the quality of the palliative care provided can be measured using quality indicators, in order to create a better understanding of this topic before coming to the specific results of the studies presented. This introductory chapter ends with the objectives and main research questions of this thesis, followed by a short description of the methods used to answer these questions.

## BACKGROUND

### Palliative care

Caring for dying people and people with non-curable diseases is not a new phenomenon.[1] "To cure sometimes, to relieve often, to comfort always" is an anonymous medieval quote describing medical care and is still relevant today.[1,2] However, specific attention to palliative care is relatively new in healthcare, with the first modern hospice, St Christopher's Hospice in London, being opened in 1967 as a key "marking point".[3] Today the need for palliative care of high quality is growing, as our population is ageing worldwide, and concomitantly the incidence and prevalence are increasing of chronic illnesses such as cardiovascular heart diseases, chronic obstructive respiratory diseases, and dementia. Consequently, in the future more and more people will be living with and dying from more complex conditions, increasing the need for palliative care even further.[4,5] Each year, at least 20 million people need palliative care at the end of life, and around 20 million more need palliative care in the years before death, leading to an annual total of at least 40 million people needing palliative care.[4] Furthermore, it has been estimated that in high-income countries, 69-82% of people who died were in need of palliative care prior to death.[5]

A multidisciplinary and holistic approach forms the core of palliative care, as is illustrated in the widely accepted definition of palliative care formulated by the World Health Organization (WHO) in 2002: *"Palliative care is an approach that improves the quality of life of patients and their families facing the problem associated with life-threatening illness, through the prevention and relief of suffering by means of early identification and impeccable assessment and treatment of pain and other problems, physical, psychosocial and spiritual"*.[6] The WHO adds some core principles to this definition that further highlight the importance of care for both patients and their relatives, even after the death when coping with the loss and grief, and the applicability of palliative care early in the course of illness.[6] Palliative care should not be limited to a specific care setting or patient group, although historically palliative care has focused on cancer patients. However, today large groups of people with non-malignant conditions need palliative care as well, including patients who suffer from cardiovascular diseases such as congestive heart failure, chronic obstructive respiratory diseases, HIV/AIDS, cerebrovascular disease, liver cirrhosis, kidney failure, neurodegenerative disorders including dementia, and the frail elderly.[4]

Palliative care provision is situated at different levels. Ideally, all healthcare professionals should be trained so that they are skilled enough to adopt a palliative care approach in care settings that only occasionally treat palliative care patients. Healthcare professionals in primary care and those having regular contact with patients with life-threatening diseases should have a good basic knowledge of and skills in relatively uncomplicated palliative care and provide "generalist palliative care". Palliative care is not the main focus of their work, but they are frequently involved in palliative care. "Specialist palliative care" on the other hand, should be available for patients with complex physical or psychological symptoms or problems. Specialist palliative care is provided by specialized, highly qualified, interdisciplinary teams whose main responsibility and activity is palliative care provision. Specialist palliative care teams can be consulted by the caregivers treating the patient, they can provide care simultaneously with those caregivers or they can take over the care of the patient. In this way, generalist and specialist palliative care can coexist and support each other.[3-5,7,8] In this thesis, we will focus on generalist palliative care.

## Quality of palliative care

There are various definitions of the concept of the "quality of care" in general,[9] based on different traditions and perspectives. Two components of the quality of care are involved in all definitions: the technical excellence of care provision, and the characteristics of interpersonal interactions between patient and caregivers.[10-12] These definitions overlap with the suggestion of the World Health Organization in 2006 that a health system should guarantee six aspects of care quality: healthcare should be effective, efficient, accessible, acceptable/patient-centered, equitable, and safe.[13] A more detailed description of these aims is given in Table 1.

**Table 1 – Six aspects of quality that health systems should improve**[13]

| ASPECT | DESCRIPTION |
|---|---|
| Effective | Delivering healthcare that is adherent to an evidence base and results in improved health outcomes for individuals and communities, based on need. |
| Efficient | Delivering healthcare in a manner which maximizes resource use and avoids waste. |
| Accessible | Delivering healthcare that is timely, geographically reasonable, and provided in a setting where skills and resources are appropriate to medical need. |
| Acceptable/ Patient-centered | Delivering healthcare which takes into account the preferences and aspirations of individual service users and the cultures of their communities. |
| Equitable | Delivering healthcare which does not vary in quality because of personal characteristics, such as gender, race, ethnicity, geographical location or socioeconomic status. |
| Safe | Delivering healthcare which minimizes risks and harm to service users. |

Whereas quality-of-care research in general started in the 1960s and 1970s, research on the quality of palliative care started more recently, and has received increasing attention in the last fifteen years.[4,7,14-17] Researchers and policy-makers have been advocating more research on the quality of palliative care, specifically research aimed at developing and using indicators of good palliative care.[4,7,14-17] One way to make the quality of care transparent, and to evaluate and monitor the quality of care is to use quality indicators.

## Quality indicators

### *Definition and background*

As their name says, quality indicators give an indication of the quality of care, they can either point out problems or identify good quality in relevant care domains.[18-20] In the 1960s and 1970s, Donabedian described a framework for quality assessment that forms the basis of most quality-of-care research methods today. He suggested quality can be evaluated on the basis of structure, process or outcome.[10] A detailed description is given in Table 2. The definition of quality indicators used in this thesis ties in with this framework. In this thesis, quality indicators are defined as "*explicitly defined measurable items referring to the outcomes, processes, or structure of care*".[21]

**Table 2 – Meaning of structure, process, and outcome of care[10]**

| CATEGORY | DESCRIPTION |
|---|---|
| Structure | Structure denotes the attributes of a setting in which care occurs. This includes the attributes of material resources (e.g. facilities and equipment), of human resources (e.g. the number and qualification of personnel) and organizational structure (e.g. medical staff organization). |
| Process | Process denotes what is actually done in giving and receiving care. It includes patient's activities in seeking care and carrying it out, as well as the practitioner's activities in making a diagnosis and recommending or implementing treatment. |
| Outcome | Outcome denotes the effects of care on the health status of patients and populations, including improvements in the patient's knowledge, salutary changes in the patient's behavior, and the patient's satisfaction with care. |

A quality indicator often consists of a numerator and denominator. The denominator describes, for instance, the patients to whom the care should be provided to and the numerator refers to the patients who actually received the recommended care. The quotient (the numerator divided by the denominator) is the indicator score.[22,23]
Some indicators have a specified performance standard,[15] a threshold value below or above which care providers should ideally score. This performance standard can be an absolute norm that is often expert based, or it can be a relative, best-practice norm, derived from the scores of the best scoring care providers (e.g. the upper quartile).[22]

Table 3 provides an overview of the quality indicators that will be explored in this thesis, to give some more concrete examples of quality indicators for palliative care.

**Table 3 – Quality Indicators explored in this thesis**

| QUALITY INDICATOR | NUMERATOR and DENOMINATOR | TYPE | PERFORMANCE STANDARD |
|---|---|---|---|
| The percentage of patients dying at home[24] | Numerator: the number of patients dying at home<br>Denominator: the total number of patients | Outcome | ≥ 95% |
| The percentage of patients who died in the location of their preference[25] | Numerator: the number of relatives who indicate that the patient died in the location of his/her preference<br>Denominator: the total number of relatives for whom this quality indicator was measured | Outcome | Not specified yet, best-practice norms will be assessed in the future |
| The percentage of time spent in hospital[24] | Numerator: the number of days in hospital during home palliative care<br>Denominator: the total number of days of home palliative care | Outcome | <10% |
| The proportion (of patients) with more than one hospitalization in the last 30 days of life[26] | Numerator: the number of patients who died from cancer and had more than one hospitalization in the last 30 days of life<br>Denominator: the number of patients who died from cancer | Outcome | <4% |
| The percentage of relatives who indicate that the patient died peacefully[25] | Numerator: the number of relatives who indicate that their relative died peacefully<br>Denominator: the total number of relatives for whom this quality indicator was measured | Outcome | Not specified yet, best-practice norms will be assessed in the future |

Quality indicators were originally developed to address care at an aggregate level, for instance at the level of a care organization.[19,21,27] They are often used for internal quality monitoring within care organizations or to provide comparative quality information to external parties.[22,25,28-33] In this way, the measurement of quality indicators can help achieve three main objectives. A first objective of quality indicators is to enhance the transparency of care quality by providing quality indicator scores to healthcare users, healthcare insurance companies, and ministries of health, for instance. Secondly, quality indicators can be used to improve the quality of care: quality indicator scores can be eye-openers and help set priorities for quality improvement, not only for professionals working in a specific care setting, but also for researchers, managers, patient organizations, and policy-makers. Thirdly, quality indicators have a role in controlling the quality of care when they are used by supervisory authorities such as the Dutch Health Care Inspectorate.[18,22,28,33]

Increasingly, quality indicators are embedded in guidelines and national care standards to make the quality as proposed in the guidelines and standards concrete and measurable. This is the case, for instance, in the recently developed Dutch Care

Standard for Palliative Care (in Dutch: *Zorgmodule Palliatieve Zorg*), which includes six indicators concerning communication with patients and shared decision making, multidisciplinary care, coordination of care, documentation of a care plan, and after-care for relatives.[34]

In addition, quality indicators also have a relationship with measurement instruments and patient-related outcome measures.[28,35] Patient-related outcome measures (PROMs) are "*standardized, validated questionnaires that are completed by patients to measure their perceptions of their own functional status and wellbeing*".[36,37] These measurement instruments and PROMs can be used to measure quality indicators, as is illustrated by the quality indicator "the percentage of patients with pain evaluated according to a numeric or other validated pain scale".[38]

### *Feasibility of quality indicators*

Quality indicators not only have to be scientifically and clinically relevant, they also have to be manageable.[35,39] Although patients and their families are an informative source of information, measuring quality indicators should be feasible and should not be an extra burden to patients or family members involved in palliative care, nor to healthcare professionals in the field. Feasibility involves not only the burden and the time investment required from healthcare professionals, patients, and relatives, but also refers to the availability of sufficient patients and relatives for the indicator measurements: there must be enough patients to make the comparison of quality indicator scores feasible.[21,25,28] Using data recorded routinely, e.g. administrative data or medical charts, or using data collected for quality purposes but not specifically focusing on quality indicators, might be ways to overcome this. Using data already available avoids the collection of new data and has low additional costs.[22,40,41] This is an essential reason why this thesis did not focus on collecting new data, but is based on existing datasets and on a systematic literature review.

### *Quality indicators for palliative care*

The systematic review presented in this thesis concerns an update of a review performed in 2007 (published in 2009). The review in 2007 revealed that eight sets of quality indicators, accounting for 142 quality indicators, had been developed for palliative care, mainly in the United States.[15] Most of these quality indicators referred to and were developed for a specific patient population or healthcare setting. Both the generalist and specialist palliative care levels were covered in these quality indicators. On the other hand, the review also revealed some limitations. The indicators referred mostly to processes and outcomes rather than the organizational structure of care.

Various domains of palliative care were covered, but indicators covering psychosocial, spiritual, and cultural domains of care were underrepresented. The scientific and methodological rigor regarding the basis and development of these quality indicators varied considerably between indicator sets, and details regarding the development process were often not available.[15]

In short, quality indicators had been developed for palliative care, but were characterized by rather quick development without rigorous testing.[15] Especially in the last few years, a lot of attention has been paid to quality indicators in the literature, at international conferences, and in policies.[4,7,14-17] It is therefore to be expected that new quality indicators would be in use to assess the quality of palliative care, or that existing quality indicators would have been explored in more depth regarding their use and psychometric qualities. Therefore, it was decided to update the systematic review, to get a more up-to-date overview of the quality indicators available at present.

Furthermore, testing if quality indicators are suitable for their purpose and if they possess good methodological properties optimizes their effectiveness in quality improvement.[21] Consequently, this thesis also focuses on measuring existing quality indicators with the help of previously collected research data. In addition, these quality indicators, which were originally developed for the comparison of different care providers and settings, will be tested to compare the quality of palliative care on a national level between different countries.

## OBJECTIVES, MAIN RESEARCH QUESTIONS, AND METHODS

This thesis consists of three parts, each with different objectives, research questions, and methodologies. A short overview of the methods used in the different parts of this thesis is presented below. A more detailed description can be found in the "Methods" section of each chapter.

The studies described did not focus on collecting new data; instead, they are based on existing datasets and a systematic review to explore the quality of palliative care using quality indicators.

## PART 1 – Existing quality indicators for palliative care

The first part of this thesis, **Chapter 2**, provides a comprehensive overview of the kind of quality indicators for palliative care that exist already, by presenting an update of the systematic review from 2007.[15] The main review question can be summarized as follows:

1. What kind of quality indicators for palliative care have been developed so far, (a) in terms of the domains of palliative care they are covering, (b) in terms of whether they relate to structures, processes or outcomes of care and (c) in terms of the methodological rigor of the development process and testing in practice?

To identify new relevant literature, searches were performed in the same databases as in the previous review:[15] PubMed, Psyc-INFO, Embase.com, and CINAHL. Identified references were eligible for inclusion if they met the following two inclusion criteria:

(a) the publication describes the development process and/or characteristics of quality indicators developed specifically for palliative care provided by care organizations or professionals;

(b) numerators and denominators are defined for the quality indicators, or the numerators and denominators can be deduced directly from the descriptions of the quality indicators, or performance standards are given.

## PART 2 – The use of quality indicators in cross-country comparisons

In the second part of this thesis, the use of quality indicators for cross-country comparisons in palliative care is explored. Comparing quality indicator scores in this way is an original strategy, since quality indicators have initially been developed to assess the quality of care at the organizational level and to make comparisons between different care organizations. The main research questions are as follows:

2. Is it feasible to calculate quality indicator scores regarding (a) place of death and (b) hospitalizations at the end of life of home-dwelling patients, on the basis of existing data from general practitioner sentinel networks?
3. Are expected differences in quality indicator scores related to actual differences in the care provided in Belgium, the Netherlands, Italy, and Spain?

The basis for this second part consists of data from a mortality follow-back study (EURO SENTI-MELC study) based on data collected by existing general practitioner (GP) sentinel networks in Belgium, the Netherlands, Italy and Spain (Castilla and León region and Valencia region). The studies described in this thesis used data from the nationally representative GP networks collected in 2009 (all countries except Spain), 2010 (all four countries), and 2011 (Spain only). The participating GPs in all four countries were representative for the general population of GPs in each country (or health districts in Italy and regions in Spain) in terms of age, gender, and geographical distribution.[42-44] In the EURO SENTI-MELC study, GPs recorded the characteristics of recently deceased patients on a weekly basis using a standardized questionnaire.

We used four quality indicators in this part. **Chapter 3** concerns two indicators regarding dying at home and dying at the place of preference. For this study, we used existing data of a home-dwelling population who did not die suddenly or unexpectedly, according to their GPs. In this way, the people in our sample were eligible for receiving palliative care.

**Chapter 4** focuses on two quality indicators concerning the duration and the frequency of hospitalizations in the last month of life. Since one of these two quality indicators was developed for a cancer population and the other one for a population receiving home care, we decided to use the data of a population of cancer patients who mainly lived at home in the last month of life. Besides the quality indicator scores themselves, feasibility, adherence of the quality indicators to existing performance standards, and association with care characteristics are assessed.

### PART 3 – Quality indicators for palliative care for residents with dementia in long-term care facilities

The third part of this thesis evaluates a specific quality indicator concerning dying peacefully, and addresses the following research questions:

4. What percentage of residents with dementia die peacefully in long-term care facilities in the Netherlands and Flanders (Belgium)?

5. Which characteristics (a) of the resident, (b) of the palliative care provided, and (c) of the specific care facility are associated with dying peacefully?

Existing data were used from two different studies: the Dutch End of Life in Dementia study (DEOLD study)[45,46] and the Dying Well with Dementia in Flanders study.[47-51]

The Dutch DEOLD study[45,46] describes the quality of dying and satisfaction with end-of-life care and decision-making from the perspectives of family members and elderly care physicians. Nineteen nursing-home organizations participated in this study,

covering a total of 34 long-term care facilities (28 nursing homes and six residential homes). Seventeen participating nursing-home organizations collected data prospectively, meaning that residents were followed from admission to the nursing home until their death or the study conclusion. Two organizations collected data retrospectively (after death) only, to increase the number of reports on decedents while avoiding the complicated logistics involved in prospective studies.[46] Data were collected between January 2007 and July 2010.
Data from the Dutch DEOLD study were used in **Chapter 5** to investigate how many residents died peacefully according to their relatives, and whether characteristics of the care provided and of the care facility were associated with the quality indicator scores for dying peacefully, in addition to characteristics of the resident.

The Dying Well with Dementia study[47-51] is a retrospective cross-sectional study, involving a representative sample of 69 Flemish long-term care facilities. Residents for whom the GP or nurse indicated that the resident “had dementia” or “was diagnosed with dementia” were selected from all the nursing-home residents who died between May and October 2010.
Data from the Dying Well with Dementia study in Flanders are discussed in **Chapter 6** to see how many residents died peacefully according to their relatives, and to explore whether dying peacefully is related to physical and psychological distress in residents with dementia.

The general discussion in **Chapter 7**, the final part of this thesis, will highlight the main findings of Chapters 2 to 6 and interpret these results thoroughly. Furthermore, some methodological considerations will be formulated, as well as implications for research, clinical practice, and policy-making.

## REFERENCES

1. Byock I. Completing the continuum of cancer care: integrating life-prolongation and palliation. CA Cancer J Clin 2000;50(2):123-132.
2. Russell IJ. Consoler toujours - To Comfort Always. J Musculoske Pain 2000;8(3):1-5.
3. Radbruch L, Payne S. White paper on standards and norms for hospice and palliative care in Europe : part 1. European Journal of Palliative Care 2009;16(6):278-289.
4. World Health Organisation (WHO) and World Palliative Care Alliance (WPCA), Connor S, Sepulveda Bermedo M, (editors). Global Atlas of Palliative Care at the End of Life. http://www.who.int/nmh/Global_Atlas_of_Palliative_Care.pdf. Accessed 19th December 2014.
5. Murtagh FEM, Bausewein C, Verne J, Groeneveld EI, Kaloki YE, Higginson IJ. How many people need palliative care? A study developing and comparing methods for population-based estimates. Palliat Med 2014;28(1):49-58.
6. World Health Organisation (WHO). Definition of Palliative Care. http://www.who.int/cancer/palliative/definition/en/. Accessed 19th December 2014; 2002.
7. Council of Europe. Recommendation Rec (2003) 24 of the Committee of Ministers to member states on the organisation of palliative care. CM 2003;130.
8. Quill TE, Abernethy AP. Generalist plus specialist palliative care--creating a more sustainable model. N Engl J Med 2013;368(13):1173-1175.
9. Campbell SM, Roland MO, Buetow SA. Defining quality of care. Soc Sci Med 2000;51(11):1611-1625.
10. Donabedian A. The quality of care. How can it be assessed? JAMA 1988;260(12):1743-1748.
11. Blumenthal D. Part 1: Quality of care--what is it? N Engl J Med 1996;335(12):891-894.
12. Brook RH, McGlynn EA, Shekelle PG. Defining and measuring quality of care: a perspective from US researchers. Int J Qual Health Care 2000;12(4):281-295.
13. World Health Organisation (WHO). Quality of Care: a process for making strategic choices in health systems. http://www.who.int/management/quality/assurance/QualityCare_B.Def.pdf. Accessed 19th December 2014; 2006.
14. EAPC Taskforce on patient-reported outcome measurement in palliative care. http://www.eapcnet.eu/Themes/Clinicalcare/Outcomemeasurement.aspx. Accessed 19th December 2014; 2012.
15. Pasman HR, Brandt HE, Deliens L, Francke AL. Quality indicators for palliative care: a systematic review. J Pain Symptom Manage 2009;38(1):145-156.
16. Ostgathe C, Voltz R. Quality indicators in end-of-life care. Curr Opin Support Palliat Care 2010;4(3):170-173.
17. National Consensus Project for Quality Palliative Care (2013). Clinical Practice Guidelines for Quality Palliative Care, Third Edition. http://www.nationalconsensusproject.org. Accessed 19th December 2014; 2013.
18. Beersen N, Kallewaard M, van Croonenborg J, van Everdingen J, van Barneveld T. Handleiding indicatorontwikkeling [Manual for Development of Indicators]. Kwaliteitsinstituut voor de Gezondheidszorg (CBO) [Quality Institute for Health Care]. http://www.zonmw.nl/nl/programmas/programma-detail/kiezen-in-zorg/consumenteninformatie-en-transparantie/. Accessed 19th December 2014; 2007.
19. Earle CC, Park ER, Lai B, Weeks JC, Ayanian JZ, Block S. Identifying potential indicators of the quality of end-of-life cancer care from administrative data. J Clin Oncol 2003;21(6):1133-1138.
20. Association of Public Health Observatories (APHO), NHS Institute for Innovation and Improvement. The Good Indicators Guide: Understanding how to use and choose indicators. http://www.apho.org.uk/resource/view.aspx?RID=44584. Accessed 19th December 2014; 2006.

21. Campbell SM, Braspenning J, Hutchinson A, Marshall MN. Research methods used in developing and applying quality indicators in primary care. BMJ 2003;326(7393):816-819.

22. Grol R, Wensing M. Kwaliteit en veiligheid in de zorg: de rol van indicatoren [Quality and safety of Care: the role of indicators]. Implementatie: Effectieve verbetering van de patiëntenzorg [Implementation: Effective improvement of patient care]. 4 ed. Amsterdam: Reed Business; 2011. p. 195-228.

23. McGlynn EA, Asch SM. Developing a clinical performance measure. Am J Prev Med 1998;14(3 Suppl):14-21.

24. Peruselli C, Marinari M, Brivio B, Castagnini G, Cavana M, Centrone G, Magni C, Merlini M, Scaccabarozzi GL, Paci E. Evaluating a home palliative care service: development of indicators for a continuous quality improvement program. J Palliat Care 1997;13(3):34-42.

25. Claessen SJJ, Francke AL, Belarbi HE, Pasman HR, van der Putten MJA, Deliens L. 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.

26. Earle CC, Neville BA, Landrum MB, Souza JM, Weeks JC, Block SD, Grunfeld E, Ayanian JZ. Evaluating claims-based indicators of the intensity of end-of-life cancer care. Int J Qual Health Care 2005;17(6):505-509.

27. Grunfeld E, Urquhart R, Mykhalovskiy E, Folkes A, Johnston G, Burge FI, Earle CC, Dent S. Toward population-based indicators of quality end-of-life care: testing stakeholder agreement. Cancer 2008;112(10):2301-2308.

28. Campbell SM, Braspenning J, Hutchinson A, Marshall M. Research methods used in developing and applying quality indicators in primary care. Qual Saf Health Care 2002;11(4):358-364.

29. Wollersheim H, Hermens R, Hulscher M, Braspenning J, Ouwens M, Schouten J, Marres H, Dijkstra R, Grol R. Clinical indicators: development and applications. Neth J Med 2007;65(1):15-22.

30. Bausewein C, Daveson B, Currow D, Downing J, Deliens L, Radbruch L, et al. EAPC White paper on Outcome Measurement in Palliative Care: Improving Practice, Attaining Outcomes and Delivering Quality Services (in press). http://www.eapcnet.eu/Themes/Clinicalcare/Outcomemeasurement/Publicationsdocuments.aspx; 2014.

31. Mainz J. Defining and classifying clinical indicators for quality improvement. Int J Qual Health Care 2003;15(6):523-530.

32. Mainz J. Developing evidence-based clinical indicators: a state of the art methods primer. Int J Qual Health Care 2003;15 Suppl 1:i5-11.

33. Berg M, Meijerink Y, Gras M, Goossensen A, Schellekens W, Haeck J, Kallewaard M, Kingma H. Feasibility first: developing public performance indicators on patient safety and clinical effectiveness for Dutch hospitals. Health Policy 2005;75(1):59-73.

34. CBO (Centraal BegeleidingsOrgaan). Zorgmodule Palliatieve Zorg 1.0 [Care Standard for Palliative Care 1.0]. http://www.cbo.nl/actueel/publicaties/zorgmodule-palliatieve-zorg-1.0. Accessed 19th December 2014; 2013.

35. Leemans K, Cohen J, Francke AL, Vander Stichele R, Claessen SJ, Van den Block L, Deliens L. 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;12:6.

36. Dawson J, Doll H, Fitzpatrick R, Jenkinson C, Carr AJ. The routine use of patient reported outcome measures in healthcare settings. BMJ 2010;340:c186.

37. Bausewein C, Daveson B, Benalia H, Simon S, Higginson I. Outcome Measurement in Palliative Care: The Essentials. http://www.eapcnet.eu/LinkClick.aspx?fileticket=-T62WTgTHtU%3d&tabid=1577. Accessed 19th December 2014; 2011.

38. Twaddle ML, Maxwell TL, Cassel JB, Liao S, Coyne PJ, Usher BM, Amin A, Cuny J. Palliative care benchmarks from academic medical centers. J Palliat Med 2007;10(1):86-98.

39. Lawrence M, Olesen F. Indicators of quality in health care. European Journal of General Practice 1997;3(3):103-108.

40. Seow H, Snyder CF, Mularski RA, Shugarman LR, Kutner JS, Lorenz KA, Wu AW, Dy SM. A framework for assessing quality indicators for cancer care at the end of life. J Pain Symptom Manage 2009;38(6):903-912.

41. 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(11):1765-1771.

42. Van den Block L, Onwuteaka-Philipsen B, Meeussen K, Donker G, Giusti F, Miccinesi G, Van Casteren V, Alonso T, Zurriaga O, Deliens L. Nationwide continuous monitoring of end-of-life care via representative networks of general practitioners in Europe. BMC Fam Pract 2013;14(1):73.

43. Donker GA. Continuous Morbidity Registration Dutch Sentinel General Practice Network 2010. Annual report. NIVEL, Utrecht, the Netherlands. 2011. Available: www.nivel.nl/peilstations. Accessed 19th December 2014.

44. Boffin N, Moreels S, Van Casteren V. The Belgian Network of Sentinel General Practices Between 2007 and 2012: A Short Report. Brussels, Belgium. Scientific Institute of Public Health, Brussels, Belgium 2013.

45. van der Steen JT, Deliens L, Ribbe MW, Onwuteaka-Philipsen BD. Selection bias in family reports on end of life with dementia in nursing homes. J Palliat Med 2012;15(12):1292-1296.

46. van der Steen JT, Ribbe MW, Deliens L, Gutschow G, Onwuteaka-Philipsen BD. Retrospective and prospective data collection compared in the Dutch End Of Life in Dementia (DEOLD) study. Alzheimer Dis Assoc Disord 2014; accepted for publication(28):1-88.

47. Vandervoort A, Van den Block L, van der Steen JT, Vander Stichele R, Bilsen J, Deliens L. Advance directives and physicians' orders in nursing home residents with dementia in Flanders, Belgium: prevalence and associated outcomes. Int Psychogeriatr 2012;24(7):1133-1143.

48. van Uden N, Van den Block L, van der Steen JT, Onwuteaka-Philipsen BD, Vandervoort A, Vander Stichele R, Deliens L. Quality of dying of nursing home residents with dementia as judged by relatives. Int Psychogeriatr 2013;25(10):1697-1707.

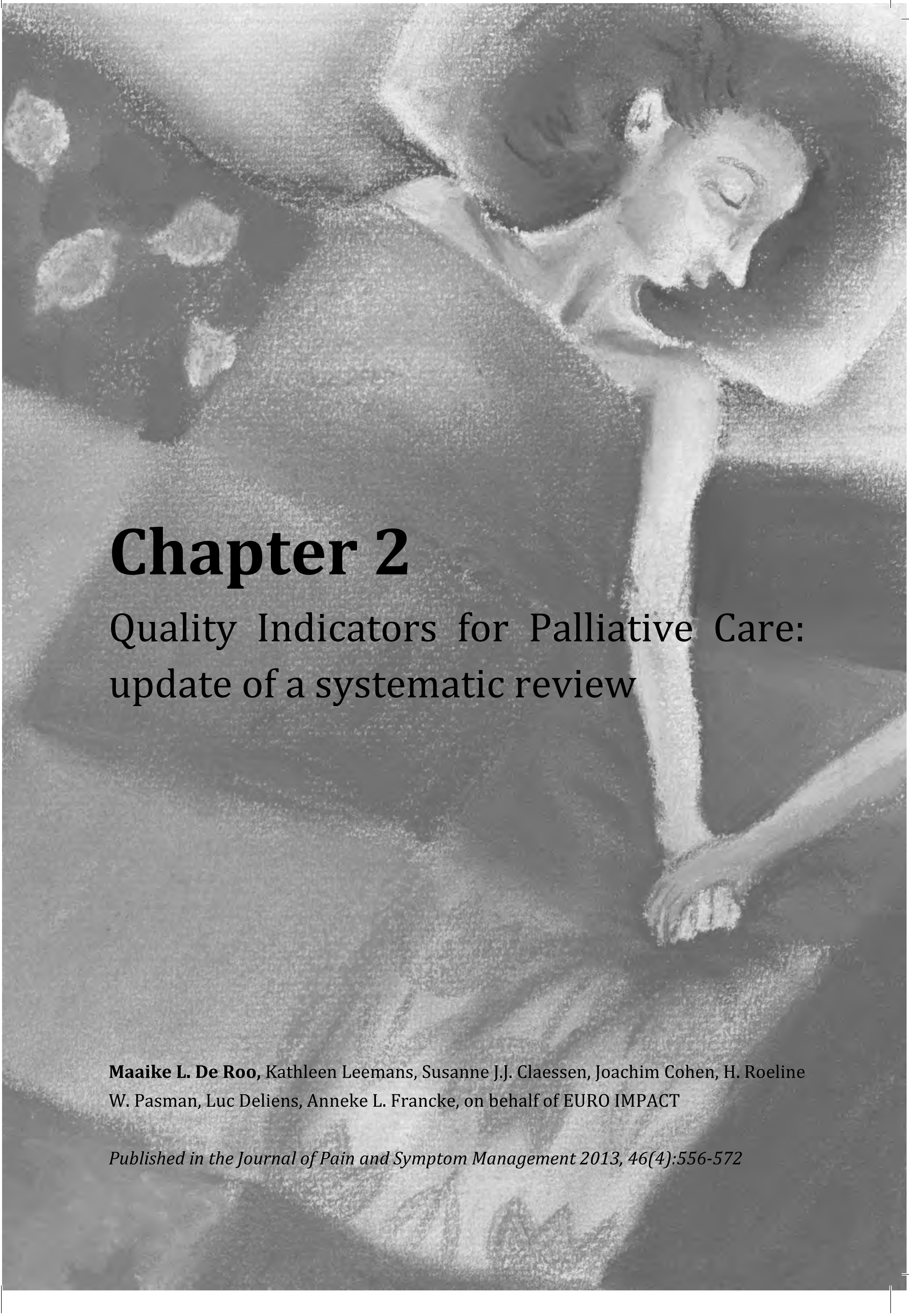
49. Vandervoort A, Van den Block L, van der Steen JT, Volicer L, Vander Stichele R, Houttekier D, Deliens L. Nursing home residents dying with dementia in Flanders, Belgium: a nationwide postmortem study on clinical characteristics and quality of dying. J Am Med Dir Assoc 2013;14(7):485-492.

50. Vandervoort A, Houttekier D, Van den Block L, van der Steen JT, Vander Stichele R, Deliens L. Advance care planning and physician orders in nursing home residents with dementia: a nationwide retrospective study among professional caregivers and relatives. J Pain Symptom Manage 2014;47(2):245-256.

51. Vandervoort A, Houttekier D, Vander Stichele R, van der Steen JT, Van den Block L. Quality of dying in nursing home residents dying with dementia: does advanced care planning matter? A nationwide postmortem study. PLoS One 2014;9(3):e91130.

# PART 1

## Existing Quality Indicators for Palliative Care



# Chapter 2

## Quality Indicators for Palliative Care: update of a systematic review

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## ABSTRACT

**CONTEXT –** In 2007, a systematic review revealed a number of quality indicators, referring mostly to palliative care outcomes and processes. Psychosocial and spiritual aspects were scarcely represented. Most publications lacked a detailed description of the development process. With many initiatives and further developments expected, an update is needed.

**OBJECTIVES –** This update gives an overview of published quality indicators for palliative care and identifies any new developments since 2007 regarding the number and type of indicators developed and the methodology applied.

**METHODS –** The same literature search as in the 2007 review was used to identify relevant publications up to October 2011. Publications describing development processes or characteristics of quality indicators for palliative care were selected by two reviewers independently.

**RESULTS –** The literature search gave 435 hits in addition to the 650 hits found in the previous review. Thirteen new publications were selected in addition to the sixteen publications selected earlier, describing seventeen sets of quality indicators and containing 326 indicators. These cover all domains of palliative care as defined by the U.S. National Consensus Project. Most indicators refer to care processes or outcomes. The extent to which methodological characteristics are described varies widely.

**CONCLUSION –** Recent developments in measuring quality of palliative care using quality indicators are mainly quantitative in nature, with a substantial number of new indicators being found. However, the quality of the development process varies considerably between sets. More consistent and detailed methodological descriptions are needed for the further development of these indicators and improved quality measurement of palliative care.

## INTRODUCTION

Quality indicators can play an important role in offering insight into the quality of care provided, and subsequently enabling improvements to care where needed.[1] Quality indicators are explicitly defined, measurable items referring to the outcomes, processes or structure of care.[2,3] They are usually described with a numerator, a denominator and/or a performance standard. Quality indicators can indicate either problems or good quality in relevant care domains.[2]

In palliative care today, there is an increasing interest in the quality of care and, more specifically, in quality indicators. In 2005 the National Consensus Project for Quality Palliative Care (NCP) in the United States published an overview of eight domains[4] covering the well-known WHO definition of palliative care.[5] Clinical guidelines were subsequently developed for each of these NCP domains in 2006 and were updated in 2009. These guidelines defined preferred practice for each domain, in an effort to guide improvement in the quality of palliative care. The NCP stated that the next step after developing these guidelines had to be the development, testing and implementation of quality indicators, to enable the determination, comparison and continual improvement of the quality of care.[4,6,7] In addition, in 2009 the Council of Europe stated that "the definition and adoption of indicators of good palliative care assessing all dimensions of care from the perspective of the patient should be encouraged".[8]

Furthermore, in 2009 Pasman *et al.* published a systematic international literature review (performed in 2007) on quality indicators for palliative care.[9] This review revealed that a number of quality indicators for palliative care had already been developed, particularly in the United States. However, the existing quality indicators showed some limitations. First, most quality indicators concerned the processes and outcomes of palliative care, whereas there were few indicators dealing with the organizational structure of palliative care. Moreover, not all domains of palliative care were covered to the same degree: there was an underrepresentation of psychosocial, spiritual and cultural domains. Finally, most indicators were restricted to one setting or patient group. The authors expressed the need for the further development of quality indicators, with detailed methodological specifications, that enable accurate assessment and monitoring of the quality of palliative care.

In general, systematic reviews synthesize existing research findings.[10] Systematic reviews need to be kept up to date,[11] particularly when there are indications that new relevant research has become available, to prevent the reviews from becoming out of date and their results becoming incomplete. The Cochrane Handbook recommends that authors should assess frequently whether relevant research is being published, so they are able to judge whether and when the review needs updating.[12] There has been rising interest in quality measurement using quality indicators in the last few years in international conferences, in policies, and in the literature. Moreover, in 2011 the European Association for Palliative Care created a task force on patient-reported outcome measurement including quality indicators in order to harmonize the approaches to quality measurement in palliative care.[13,14]

Therefore, it is likely that new sets of quality indicators will have been developed and that some of the methodological characteristics of the indicators in the previous review will have been explored in more detail. In view of the above-mentioned recommendation and our expectations that the increased attention would result in new developments in this area, we decided to update the systematic review of Pasman *et al.*[9]

This article presents an updated systematic review describing the state of the art of quality indicators for palliative care. We will describe (a) the extent to which these quality indicators cover the eight domains of palliative care identified by the National Consensus Program, (b) whether the quality indicators cover outcomes, processes or the structure of palliative care, and (c) the methodological characteristics of the quality indicators. We were particularly interested in any new developments, especially developments that overcome any of the shortcomings found by Pasman *et al*.

## METHODS

### Data sources and searches

All references included in the review of Pasman *et al*. were also included in the updated review. To identify new relevant literature, searches were performed in the same databases as in the Pasman review: PubMed, PsycINFO (via OvidSP), EMBASE.com and CINAHL (via EBSCO). The search period ran from the inception of the databases to October 7, 2011. No limitations regarding language were applied. Controlled terms from MeSH in PubMed, thesaurus terms from PsycINFO, Emtree in

EMBASE.com and CINAHL Headings in CINAHL were used as well as free text terms. Search terms expressing palliative care were combined with search terms comprising quality indicators. The PubMed search strategy is displayed in Appendix 1; the search strategies performed in the other databases were comparable and are available on request.

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

### Inclusion criteria and study selection

Newly identified references were eligible for inclusion if they met the following inclusion criteria, also used in the Pasman *et al*. 2007 review:

(a) the publication describes the development process and/or characteristics of quality indicators developed specifically for palliative care provided by care organizations or professionals;

(b) numerators and denominators are defined for the quality indicators, *or* the numerators and denominators can be deduced directly from the descriptions of the quality indicators, *or* performance standards are given.

Literature in a language other than English could be included in this systematic review if an English translation of the indicators was available (either included in the literature or available on request). Editorials, letters to the editor, comments and narrative case reports were excluded. Indicators focusing on national palliative care policy or the organization of palliative care at a national level (e.g. Ahmedzai *et al.*[15]) were also excluded. Publications describing the application of existing quality indicators in clinical practice or reviews of several (sets of) quality indicators without any new developments in addition to the previous review of Pasman et al. were not included in this review.

Newly identified references were screened by two reviewers independently (K.L. and J.C. or S.J.J.C. and M.L.D.R.) in a two-stage inclusion process. In the first stage, references were screened independently by title and abstract. All references deemed eligible for inclusion proceeded to the second selection stage, in which two reviewers independently examined the remaining references by reading the full texts. Any discrepancies between reviewers' selections were discussed until consensus was obtained, or else one of the other review authors (A.L.F.) was consulted.

The reference lists of all publications selected in the second stage were checked to identify any relevant publications that had not been found in the computerized searches.

### Data extraction

The data extraction form designed by Pasman *et al.*[9] was used to extract relevant data from the included literature. The extracted information concerned a general description of the quality indicator, the target population, the applicable setting and the type of quality indicator (whether it describes an outcome, a process or a structure of palliative care). If relevant information regarding characteristics was lacking, the publication authors were contacted for additional information. If multiple publications dealt with the same indicator set, the descriptions of the quality indicators in the most recent publication were used for this review. Data extraction forms were completed by two reviewers (K.L. and M.L.D.R. or S.J.J.C. and M.L.D.R.) independently. Discrepancies between reviewers were discussed and in those cases where a consensus could not be reached, one of the other coauthors (A.L.F.) was consulted.
If after completing the extraction forms it seemed that certain individual quality indicators did not fulfill the inclusion criteria described earlier in this section (e.g. numerator and denominator were not defined for this specific indicator), they were not considered for further analysis. Consequently, not all indicator sets were selected in their entirety.

Subsequently, the quality indicators were categorized by two reviewers independently (K.L. and M.L.D.R. or S.J.J.C. and M.L.D.R.) into the domains of palliative care defined by the National Consensus Program.[4,6,7] These domains are as follows:
(1) *"Structure and Process of Care"* (e.g. organizing training and education for professionals; providing continuity of care).
(2) *"Physical Aspects of Care"* (e.g. measuring and documenting pain and other symptoms; assessing and managing symptoms and side effects).
(3) *"Psychological and Psychiatric Aspects of Care"* (e.g. measuring, documenting and managing anxiety, depression and other psychological symptoms, assessing and managing the psychological reactions of patients/families).
(4) *"Social Aspects of Care"* (e.g. conducting regular patient/family care conferences to provide information, to discuss goals of care and to offer support to patient or family; developing and implementing comprehensive social care plans).
(5) *"Spiritual, Religious, and Existential Aspects of Care"* (e.g. providing information about availability of spiritual care services to patient or family).

(6) *"Cultural Aspects of Care"* (e.g. incorporating cultural assessments such as the locus of decision making, preferences of patient or family regarding the disclosure of information and truth telling, language, and rituals).
(7) *"Care of the Imminently Dying Patient"* (e.g. recognizing and documenting the transition to the active dying phase; ascertaining and documenting patient/family wishes about the place of death; implementing a bereavement care plan).
(8) *"Ethical and Legal Aspects of Care"* (e.g. documenting patient/surrogate preferences for care goals, treatment options and the care setting; making advance directives; promoting advanced care planning).

### Methodological assessment

As in the previous review,[9] the quality indicators were assessed methodologically using the AIRE Instrument (Appraisal of Indicators through Research and Evaluation).[16] This instrument consists of 20 items, subdivided into four categories. Three of these categories were used for the methodological assessment in this review (see Appendix 2). The fourth category, "purpose, relevance and organizational context", was less relevant for this review, because the items in this category reflect the relevance of the quality indicators within a particular context rather than the methodological characteristics. Each item's score ranges from 1 to 4, where 1 is "strongly disagree" (confident that the criterion has not been fulfilled or no information was available), 2 and 3 are "disagree/agree" (unsure whether the criterion has been fulfilled; answer "agree" or "disagree", depending on the extent to which the criterion has been fulfilled), and 4 is "strongly agree" (confident that the criterion has been fulfilled).

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

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

three or nine) and the number of evaluators (two). The minimum possible score was calculated at the same time by using the minimum score per item (score of 1).

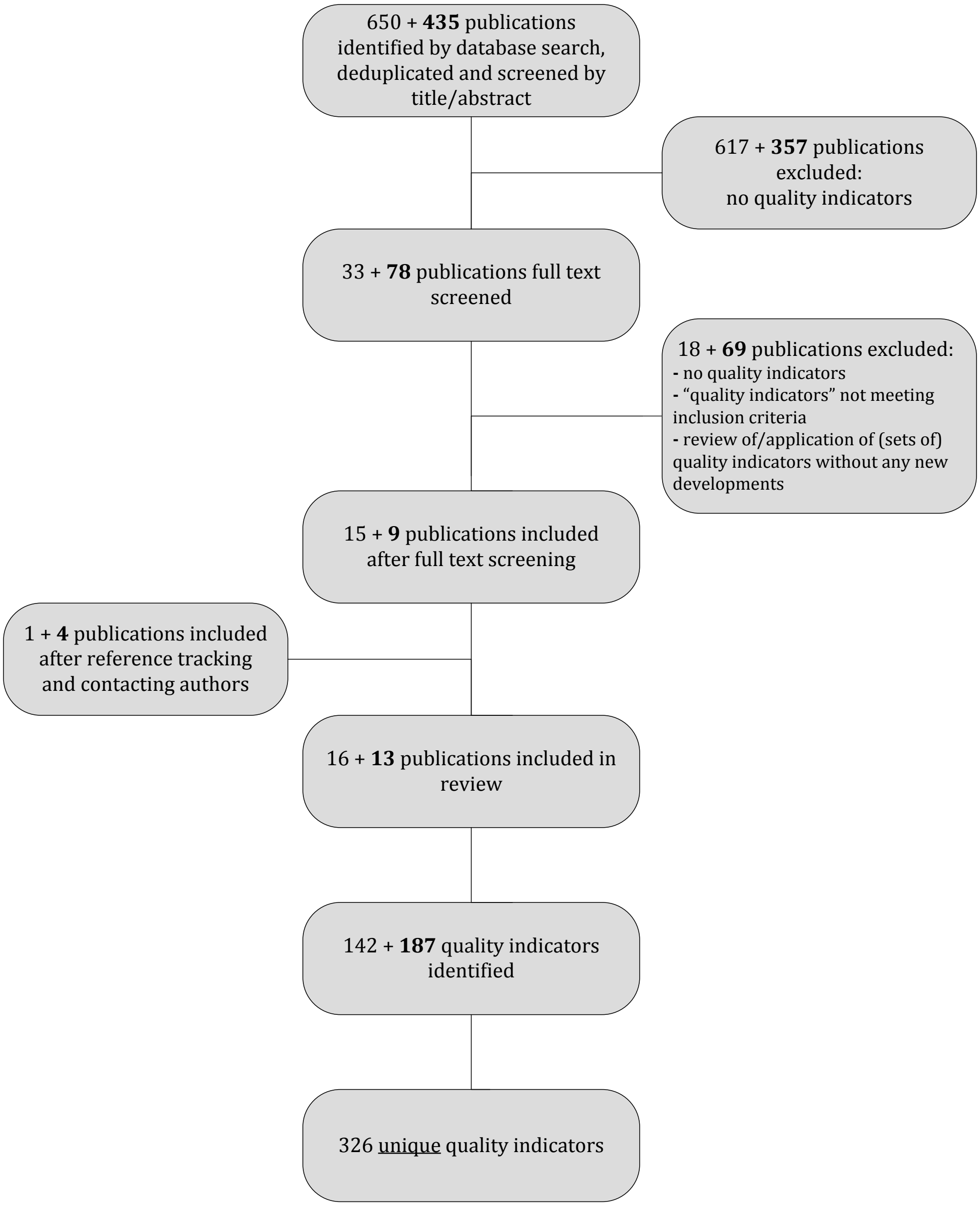
The standardized category score is the total score per category, minus the minimum possible score for that category, divided by the maximum possible score minus the minimum possible score times 100%. This standardized score ranges between 0% and 100%, with a higher score indicating a higher methodological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

## RESULTS

### Results of the searches

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

**Figure 1 – Flow chart of the literature search**



First number marks the results found in the original review by Pasman *et al.*, 2009.
Second number (in bold) indicates the additional results found in this review.

These thirteen new publications described a total of nine new sets, in addition to the eight sets of quality indicators found by Pasman *et al*., as presented in Table 1 (the new sets are marked with NEW in Table 1). Eight of these sets are completely new, whereas one set[21] is an adapted and shortened version of a set found in the previous review.

The new sets of quality indicators contained 187 partly overlapping quality indicators, in addition to the 142 quality indicators found in the previous review. This resulted in 326 unique indicators (three indicators were identical to indicators found in the previous review), described in more detail in Appendix 3.

**General overview of the quality indicator sets found**

Most sets in the original review were developed in the United States, whereas the new sets included some developed in the Netherlands, Japan, and the United Kingdom (for more details see Table 1). Various palliative care settings and patient populations are covered. Concerning palliative cancer care, three new sets[18-20,22,23,34] were found in addition to the two sets found in the previous review.[32,33,49,50] One set was found in the previous review with regard to end-of-life care for the vulnerable elderly;[30,38,42,47,49] it subsequently was shortened and adapted for use in the Netherlands.[21] Concerning palliative care in a hospice setting, two sets were found: one set had already been found in the previous review,[50] but this update revealed an additional set focusing on hospice or palliative care.[25] In the previous review one set was found for end-of-life care in intensive care units,[39,40] palliative nursing home care,[35] home palliative care,[41] and hospital-based palliative care[46] (one set for each of the four settings). In addition, four new sets were found with a relatively broad focus. One set applies to all settings where palliative care is provided for adult patients and was developed in the Netherlands,[17,29] one set was developed for use in a variety of specialist care settings in Australia,[24,28] and two sets focus on palliative care in several settings in the United Kingdom.[26,27]

### Table 1 – Characteristics of quality indicator sets

| FIRST AUTHOR, YEAR, COUNTRY, REFERENCES | POPULATION | SETTING | NUMBER OF INDICATORS: TOTAL AND PER TYPE | NUMBER OF INDICATORS PER DOMAIN | EXAMPLE OF INDICATOR (TYPE/DOMAIN) |
|---|---|---|---|---|---|
| Earle, 2006, USA,[32,33,50] | Patients with cancer | Not specified | Total: 7<br>Outcome: 0<br>Process: 7<br>Structure: 0 | Domain 1: 3<br>Domain 2: 0<br>Domain 3: 0<br>Domain 4: 0<br>Domain 5: 0<br>Domain 6: 0<br>Domain 7: 4<br>Domain 8: 0 | "Proportion with more than one hospitalization in the last 30 days of life"<br>Numerator: Patients who died from cancer and had more than one hospitalization in the last 30 days of life<br>Denominator: Patients who died from cancer<br>Performance standard: < 4%<br>(Process/Domain 7) |
| $^{\text{NEW}}$ Grunfeld, 2008, USA,[18,34] | Cancer patients in their last six months of life | All settings where end-of-life care is provided | Total: 10<br>Outcome: 4<br>Process: 6<br>Structure: 0 | Domain 1: 4<br>Domain 2: 2<br>Domain 3: 0<br>Domain 4: 0<br>Domain 5: 0<br>Domain 6: 0<br>Domain 7: 4<br>Domain 8: 0 | "Enrollment in palliative care within three days of death"<br>Numerator: Number of cases enrolled in palliative care within three days prior to death<br>Denominator: All cases enrolled in palliative care<br>(Process/Domain 7) |
| Yabroff, 2004, USA,[49] | Patients with cancer (as prototype) | Not specified | Total: 10<br>Outcome: 5<br>Process: 5<br>Structure: 0 | Domain 1: 8<br>Domain 2: 1<br>Domain 3: 1<br>Domain 4: 0<br>Domain 5: 0<br>Domain 6: 0<br>Domain 7: 0<br>Domain 8: 0 | "Percentage of patients and family/caregivers within health facilities or systems that understand and are satisfied with provider communication about prognosis"<br>No further specifications<br>(Outcome/Domain 1) |

| | | | | | |
|---|---|---|---|---|---|
| NEW Lorenz, 2009, USA,[22,23] | Adults with cancer | Major clinical settings where cancer patients seek care, including general practice and oncology settings | Total: 41<br>Outcome: 0<br>Process: 41<br>Structure: 0 | Domain 1: 2<br>Domain 2: 33<br>Domain 3: 3<br>Domain 4: 0<br>Domain 5: 0<br>Domain 6: 0<br>Domain 7: 0<br>Domain 8: 3 | "IF a cancer patient is admitted to a hospital THEN there should be screening for the presence or absence of pain"<br>No further specifications<br>(Process/Domain 2) |
| NEW Miyashita, 2008, Japan,[19,20] | Terminal cancer patients and their family members | All clinical settings, including general wards, palliative care units and home care | Total: 37<br>Outcome: 19<br>Process: 18<br>Structure: 0 | Domain 1: 6<br>Domain 2: 8<br>Domain 3: 4<br>Domain 4: 5<br>Domain 5: 2<br>Domain 6: 1<br>Domain 7: 1<br>Domain 8: 10 | "Symptom control: Physician's prescription order for dyspnea"<br>Numerator: Number of patients for whom this indicator was documented on admission or within the last 2 weeks of the hospitalization<br>Denominator: All patients who died (retrospectively identified)<br>(Process/Domain 2) |
| Peruselli, 1997, Italy,[41] | Terminal patients | Home care | Total: 54<br>Outcome: 43<br>Process: 11<br>Structure: 0 | Domain 1: 17<br>Domain 2: 18<br>Domain 3: 14<br>Domain 4: 3<br>Domain 5: 0<br>Domain 6: 0<br>Domain 7: 2<br>Domain 8: 0 | "Palliative care services must meet the physical, psychological, social and spiritual needs of patients"<br>Numerator: Number of patients with global scores for fatigue (TIQ scale) not increased over initial score during final week of care (if initial score on the same scale > 25)<br>Denominator: Total patients x 100<br>Performance standard: 75%<br>(Outcome/Domain 2) |
| Keay, 1994, USA,[35] | Terminally ill in nursing homes | Nursing home | Total: 7<br>Outcome: 1*<br>Process: 7<br>Structure: 0 | Domain 1: 0<br>Domain 2: 3<br>Domain 3: 1<br>Domain 4: 0<br>Domain 5: 0<br>Domain 6: 0<br>Domain 7: 1<br>Domain 8: 2 | "If terminally ill patient is reported to be in pain, this is addressed by the physician and active attempts are made to reduce pain"<br>Exclusion: Minor pain symptoms in cognitively intact patients<br>Performance standard: 100%<br>(Process + Outcome/Domain 2) |

| | | | | | |
|---|---|---|---|---|---|
| Lorenz, 2007, USA,[30,36,38,42,47] | Vulnerable elderly | Not specified[†] | Total: 23<br>Outcome: 0<br>Process: 23<br>Structure: 0 | Domain 1: 2<br>Domain 2: 8<br>Domain 3: 1<br>Domain 4: 1<br>Domain 5: 0<br>Domain 6: 0<br>Domain 7: 1<br>Domain 8: 10 | "IF a vulnerable elder has documented treatment preferences to withhold or withdraw life-sustaining treatment (e.g. DNR order, no tube feeding, no hospital transfer), THEN these treatment preferences should be followed, BECAUSE medical care should aim to be consistent with a patient's preferences"<br>No further specifications<br>(Process/Domain 8) |
| NEW van der Ploeg, 2008, the Netherlands,[21] | Vulnerable elders<br>Adapted and shortened version of the set by Lorenz et al. 2007 | Care for vulnerable elders in general, this publication is currently focusing on care provided by the general practitioner | Total: 6[‡]<br>Outcome: 2<br>Process: 4<br>Structure: 0 | Domain 1: 0<br>Domain 2: 4<br>Domain 3: 2<br>Domain 4: 1<br>Domain 5: 0<br>Domain 6: 0<br>Domain 7: 1<br>Domain 8: 1 | "IF a vulnerable elder dies with a progressive incurable disease (for example metastatic cancer, or dementia) THEN there should be evidence within 6 months prior to death that they received a comprehensive assessment including:<br>• Pain;<br>• Anxiety, depression;<br>• Vomiting and dyspnea;<br>• Spiritual and existential concerns;<br>• Caregiver burdens/need for practical assistance;<br>• Wishes concerning medical treatment and care at the end of life; a discussion about and if possible the determination of a surrogate decision maker"<br>No further specifications<br>(Process/Domains 2,3,4 and 8) |
| National Hospice and Palliative Care Organization (NHPCO), 2006, USA,[50] | Patients enrolled in hospice program | Not specified | Total: 8<br>Outcome: 4<br>Process: 4<br>Structure: 0 | Domain 1: 1<br>Domain 2: 3<br>Domain 3: 2<br>Domain 4: 0<br>Domain 5: 0<br>Domain 6: 0<br>Domain 7: 2<br>Domain 8: 0 | "Family evaluation of hospice care: Symptom management questions (to family): While under the care of hospice, did the patient have any feelings of anxiety or sadness? How much help in dealing with these feelings did the patient receive?"<br>Numerator: Those who received too much or too little help concerning anxiety/sadness<br>Denominator: Those who experience anxiety/sadness<br>Exclusion: Patients who are not enrolled in a hospice program or have disenrolled from a hospice program. Live discharged are excluded<br>(Outcome/Domain 3) |

| | | | | | |
|---|---|---|---|---|---|
| NEW Schenck, 2010, USA,[25] | Patients in hospice or palliative care | Hospice or palliative care | Total: 28<br>Outcome: 10[*]<br>Process: 19<br>Structure: 0 | Domain 1: 2<br>Domain 2: 17<br>Domain 3: 3<br>Domain 4: 0<br>Domain 5: 1<br>Domain 6: 0<br>Domain 7: 0<br>Domain 8: 5 | "For patients who screened positive for pain, the percent with any treatment within one day of screening"<br>Numerator: Number of patients with (0≤pain treatment time≤1) and (pain treatment="Y") [Pain Treatment Time = date of treatment – pain assessment date]<br>Denominator: Patients with pain<br>(Process/Domain 2) |
| Nelson, 2006 and Mularski, 2006, USA,[39,40,§] | Critically ill | Intensive care units (ICU) | Total: 21[†]<br>Outcome: 2[*]<br>Process: 15<br>Structure: 5 | Domain 1: 9<br>Domain 2: 5<br>Domain 3: 0<br>Domain 4: 2<br>Domain 5: 1<br>Domain 6: 0<br>Domain 7: 1<br>Domain 8: 4 | "Documentation of offering of psychosocial support within the first 72 hours of admission to the ICU"<br>Numerator: Total number of patients in the ICU for >72 hours with psychosocial support offered to the patient or family by any team member<br>Denominator: Total number of patients in the ICU for >72 hours<br>Exclusion: Comatose patients (e.g. Glasgow Coma Score of 2 or 3) with no family member or friend identified<br>(Process/Domain 4) |
| Twaddle , 2007, USA,[46] | Patients in hospitals | Hospital | Total: 11<br>Outcome: 2<br>Process: 9<br>Structure: 0 | Domain 1: 4<br>Domain 2: 6<br>Domain 3: 1<br>Domain 4: 0<br>Domain 5: 0<br>Domain 6: 0<br>Domain 7: 0<br>Domain 8: 0 | "Percentage of all patients with documentation of dyspnea assessment within 48 hours of admission"<br>Performance standard: 90%<br>(Process/Domain 2) |

| | | | | | |
|---|---|---|---|---|---|
| NEW Claessen, 2011, the Netherlands,[17,29] | Adult patients receiving palliative care | All settings in which palliative care is being provided for adult patients in the Netherlands | Total: 11<br>Outcome: 10<br>Process: 1<br>Structure: 0 | Domain 1: 1<br>Domain 2: 4<br>Domain 3: 2<br>Domain 4: 0<br>Domain 5: 2<br>Domain 6: 0<br>Domain 7: 1<br>Domain 8: 1 | "Care for psychosocial well-being of patients: percentage of patients who feel depressed"<br>Numerator: The number of patients with a feeling depressed score of 4 or above on the NRS (average over three days)<br>Denominator: The total number of patients for whom this indicator is measured<br>Exclusion: Patients with moderate to (very) severe cognitive impairments, young children, psychiatric and/or confused patients, and comatose and deeply sedated patients<br>(Outcome/Domain 3) |
| NEW Eagar, 2010, Australia,[24,28] | Not specified | Specialist palliative care settings | Total: 3<br>Outcome: 2<br>Process: 0<br>Structure: 1 | Domain 1: 2<br>Domain 2: 1<br>Domain 3: 0<br>Domain 4: 0<br>Domain 5: 0<br>Domain 6: 0<br>Domain 7: 0<br>Domain 8: 0 | "The percentage of patients and their family members or carers, who have contact with the palliative care service within 48h, taking into account the patient's phase and functional status"<br>No further specifications<br>(Structure/Domain 1) |
| NEW Quality Markers, 2009, UK,[26] | Not specified | Primary care, acute hospitals, community hospitals, care homes, specialist palliative care inpatient facilities, providers of specialist end of life care services in the community, district/community nursing services, ambulance services, out of hours medical services[‖] | Total: 34<br>Outcome: 9<br>Process: 11<br>Structure: 14 | Domain 1: 23<br>Domain 2: 0<br>Domain 3: 0<br>Domain 4: 2<br>Domain 5: 0<br>Domain 6: 0<br>Domain 7: 5<br>Domain 8: 4 | "Proportion of individuals whose preferred place for care has been recorded"<br>No further specifications<br>(Outcome/Domain 8) |

| | | | | | |
|---|---|---|---|---|---|
| [NEW] End of Life Care Quality Assessment, 2011, UK,[27] | Not specified | Commissioners, primary care, acute hospitals, community services, including community hospitals, care homes, specialist palliative care inpatient services, specialist palliative care community services, ambulance services, out of hours services[\|\|] | Total: 18[¶]<br>Outcome: 4[**]<br>Process: 13<br>Structure: 3 | Domain 1: 11<br>Domain 2: 0<br>Domain 3: 0<br>Domain 4: 1<br>Domain 5: 0<br>Domain 6: 0<br>Domain 7: 3<br>Domain 8: 4 | "Individuals have an agreed care plan"<br>Numerator: Number of deceased patients with care plan in place.<br>Denominator: Total deaths for same catchment and time period<br>Performance standard: Care plans in place for all patients approaching the end of life<br>(Process/Domain 8) |

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

[NEW] indicates that these quality indicator sets have been found in this update.

* One indicator contained outcome and process of care.

† Saliba *et al.*[42] tested the feasibility of a selection of the quality indicators for nursing home residents.

‡ One indicator suits four NCP-categories.

§ Both Nelson *et al.* and Mularski *et al.* used the same preliminary set of quality indicators for the ICU,[31] but partly selected different quality indicators. The total number of quality indicators in this set is the total of both sets.

|| Not all indicators do apply to all settings.

¶ Two indicators suit two NCP-categories.

** Two indicators contained outcome and process of care.

### Quality indicators per domain of palliative care

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

A relatively large number of quality indicators was also found (44 indicators) for “Ethical and Legal Aspects of Care”, mostly concerning advance care planning (e.g. Lorenz *et al*. 2007, ELCQuA 2011, see Table 1). For “Psychological and Psychiatric Aspects of Care”, 33 quality indicators were found, concerning issues as anxiety and depression, and the presence of emotional support (e.g. NHPCO 2006, Claessen *et al*. 2011, see Table 1). Twenty-six were found for the domain “Care of the Imminently Dying Patient”, mainly concerning the aggressiveness of care, and bereavement (e.g. Earle *et al*. 2006, Grunfeld *et al*. 2008, see Table 1). For “Social Aspects of Care” fifteen quality indicators were found, there were six for “Spiritual, Religious, and Existential Aspects of Care” and only one for “Cultural Aspects of Care”.

### Outcome, process or structure quality indicators

Most quality indicators (199 indicators) concerned the process of care. They mainly addressed the documentation of the care that was actually provided to/received by the patient (see Table 2) (e.g. van der Ploeg *et al.* 2008, see Table 1). Also a substantial number of outcome indicators was found (117 indicators). Only 22 indicators for the structure of palliative care were found, with fourteen indicators coming from one set.[26]

**Table 2 – Number of quality indicators identified per domain according to the type of indicator**

| DOMAINS | TYPE OF INDICATOR<br>OUTCOME | PROCESS | STRUCTURE | TOTAL |
|---|---|---|---|---|
| 1: Structure and Process of Care[*,†] | 20 | 55 | 21 | **95**[*] |
| 2: Physical Aspects of Care[†,‡] | 41 | 74 | 0 | **112**[‡] |
| 3: Psychological and Psychiatric Aspects of Care[†] | 21 | 12 | 0 | **33** |
| 4: Social Aspects of Care[†] | 4 | 11 | 0 | **15** |
| 5: Spiritual, Religious and Existential Aspects of Care | 5 | 1 | 0 | **6** |
| 6: Cultural Aspects of Care | 1 | 0 | 0 | **1** |
| 7: Care of the Imminently Dying Patient[*,†] | 9 | 17 | 1 | **26**[*] |
| 8: Ethical and Legal Aspects of Care[*,†] | 16 | 29 | 0 | **44**[*] |
| **TOTAL** | **117** | **199** | **22** | **326**[*,†,‡] |

* One indicator contained outcome and process of care.

† Some indicators suit several domains: Indicator no. 30 (see Appendix 3) suits Domains 1 and 8. Indicator no. 200 suits Domains 2, 3, 4 and 8. Indicator no. 284 suits Domains 7 and 8.

‡ Three indicators contained outcome and process of care.

### Methodological characteristics of quality indicators

There was wide variation in the information presented about the methodological characteristics of the identified sets of quality indicators. Some indicator sets and their development process were described in detail, with a clear definition of numerators, denominators and/or performance standards, whereas other indicator sets were lacking more detailed information on methodology (see Table 3). Furthermore, these sets differ in the extent to which they have been tested in daily practice. For most of the indicator sets, the highest scores were obtained for the items "Scientific evidence" and "Stakeholder involvement", and the lowest scores for the item "Additional evidence, formulation and usage". The set of Schenck *et al.*[25] and the set of Earle *et al.*[32,33,50] had high scores for all three categories, the set of Peruselli *et al.*[41] and the Quality Markers[26] set had the lowest scores.

Items that scored particularly poorly were "the indicator has been formally endorsed", "the supporting evidence has been critically appraised", "the indicator has sufficient discriminative power" and "specific instructions for presenting and interpreting the indicator results are provided". These poor scores were also found in the original review (Data not shown).

## Table 3: Methodological characteristics of sets of quality indicators (AIRE Instrument)

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

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

* References 31, 43-45, 48 were used for completing the AIRE Instrument, because they contain additional information about the development of the quality indicators that is necessary for completing the AIRE Instrument.

† Nelson *et al.* and Mularski *et al.* both used the same preliminary set of quality indicators for the ICU,[31] but partly selected different quality indicators. In the Nelson *et al.* publication, some of the quality indictors are presented in more detail. Therefore, we decided to fill in the AIRE Instrument for each publication separately.

## DISCUSSION

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

### Domains of palliative care

All eight domains defined by the National Consensus Program were covered by the quality indicators identified in this review, but only five of these domains had a substantial number of indicators ("Structure and Process of Care", "Physical Aspects of Care", "Psychological and Psychiatric Aspects of Care", "Care of the Imminently Dying Patient" and "Ethical Aspects of Care"). The domains "Social Aspects of Care" and "Spiritual, Religious and Existential Aspects of Care" were covered by fifteen and six indicators respectively, and "Cultural Aspects of Care" was covered by only one quality indicator identified in this review.

Although Pasman *et al.*[9] suggested that extra attention should be paid to the development of quality indicators in these latter domains, no such efforts have been made since. Only one set of quality indicators in Japan[19] covered all eight domains. However, for some indicators it can be debated which domain they belong to. As pointed out in Table 2, some indicators suit more than one domain. This unequal distribution of the indicators across the eight domains could also be indicative of how daily palliative practice pays more attention to themes such as symptom control and communication and less to psychosocial or spiritual support. The relative underrepresentation of some domains does not necessarily need to be seen as problematic. However, if palliative care is claiming to cover these aspects or domains of care, adequate indicators are necessary to monitor the quality of these aspects of care.

## Types of quality indicators

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

In most situations a quality indicator set needs to be broad and comprehensive, that is, referring to all types of patients and institutions; hence all three types of indicators should be taken into account. In some cases, for example, when being assigned by the government, the choice can be made to limit the number of quality indicators being developed and it can be desirable to focus particularly on outcome indicators. Nevertheless, several authors suggest that a combination of structure, process, and outcome indicators may be most appropriate to measure the quality of palliative care.[2,4,53,55-57]

## Developments since the 2007 review

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

**Methodological characteristics of quality indicators**

The indicator sets studied in this review differed in the quality of their methodology and the information available about their development. Some sets included very detailed information on the developmental process and the definitions of numerators and denominators. Other sets lacked important information on these subjects. The sets by Earle *et al.*[6,32,33] and Schenk *et al.*[25] had the highest methodological scores following the AIRE instrument. The developmental process of these sets was described very precisely and elaborately. Moreover both of these sets are officially accepted by a national organization. These sets with high scores on the AIRE instrument might well be suitable for use in daily palliative practice.[9] The set of Peruselli *et al.*[41] and the Quality Markers,[26] two sets with low scores on the AIRE categories, were not described in any detail and there was no information on the development process to be found in the literature.

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

### Strengths and limitations of this systematic review

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

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

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

## CONCLUSION

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

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## REFERENCES

1. Davies E, Higginson IJ, eds. The solid facts: Palliative care. Geneva: World Health Organisation, 2004.

2. Campbell SM, Braspenning J, Hutchinson A, Marshall MN. Research methods used in developing and applying quality indicators in primary care. BMJ 2003;326(7393):816-819.

3. Donabedian A. The quality of care. How can it be assessed? JAMA 1988;260(12):1743-1748.

4. Ferrell BR. Overview of the domains of variables relevant to end-of-life care. J Palliat Med 2005;8(Suppl 1):S22-S29.

5. World Health Organization (WHO). Definition of palliative care. 2008. Available from http://www.who.int/cancer/palliative/definition/en/. Accessed 19th December 2014.

6. National Consensus Project for Quality Palliative Care. 2009. Clinical Practice Guidelines for Quality Palliative Care, 2nd ed. Available from http://www.nationalconsensusproject.org. Accessed 19th December 2014.

7. Ferrell B, Connor SR, Cordes A, Dahlin CM, Fine PG, Hutton N, Leenay M, Lentz J, Person JL, Meier DE, Zuroski K. The national agenda for quality palliative care: the National Consensus Project and the National Quality Forum. J Pain Symptom Manage 2007;33(6):737-744.

8. Council of Europe. Recommendation Rec (2003) 24 of the Committee of Ministers to member states on the organisation of palliative care. CM 2003;130. Available from http://www.coe.int/T/DG3/Health/Source/Rec(2003)24_en.pdf. Accessed 19th December 2014.

9. Pasman HR, Brandt HE, Deliens L, Francke AL. Quality indicators for palliative care: a systematic review. J Pain Symptom Manage 2009;38(1):145-156.

10. Moher D, Tsertsvadze A, Tricco AC, Eccles M, Grimshaw J, Sampson M, Barrowman N. When and how to update systematic reviews. Cochrane Database Syst Rev 2008;MR000023.

11. Moher D, Tsertsvadze A, Tricco AC, Eccles M, Grimshaw J, Sampson M, Barrowman N. A systematic review identified few methods and strategies describing when and how to update systematic reviews. J Clin Epidemiol 2007;60(11):1095-1104.

12. Higgins JPT, Green S, eds. Cochrane Handbook for Systematic Reviews of Interventions, Version 5.1.0 [updated March 2011]. The Cochrane Collaboration, 2011. Available from http://www.cochrane-handbook.org. Accessed 19th December 2014.

13. European Association for Palliative Care. EAPC Taskforce on patient-reported outcome measurement in palliative care. 2012. Available from http://www.eapcnet.eu/Themes/Clinicalcare/Outcomemeasurement.aspx. Accessed 19th December 2014.

14. Simon S, Higginson I, Harding R, Daveson B, Gysels M, Deliens L, Echteld M, Radbruch L, Toscani F, Krzyzanowski D, Costantini M, Downing J, Ferreira P, Benalia A, Bausewein C. Enhancing patient-reported outcome measurement in research and practice of palliative and end-of-life care. Support Care Cancer 2012;20(7):1573-1578.

15. Ahmedzai SH, Gómez-Batiste X, Engels Y, Hasselaar J, Jaspers B, Leppert W, et al. Assessing organisations to improve palliative care in Europe. Nijmegen: Vantilt Publishers, 2010.

16. de Koning J, Smulders A, Klazinga N. Appraisal of Indicators through Research and Evaluation (AIRE). 2007. Available from http://www.ha-ring.nl/download/literatuur/Handleiding%20Indicatorenontwikkeling%20CBO.pdf. Accessed 19th December 2014.

17. Claessen SJJ, Francke AL, Belarbi HE, Pasman HR, van der Putten MJA, Deliens L. 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.

18. Grunfeld E, Urquhart R, Mykhalovskiy E, Folkes A, Johnston G, Burge FI, Earle CC, Dent S. Toward population-based indicators of quality end-of-life care: testing stakeholder agreement. Cancer 2008;112(10):2301-2308.

19. Miyashita M, Nakamura A, Morita T, Bito S. Identification of quality indicators of end-of-life cancer care from medical chart review using a modified Delphi method in Japan. American Journal of Hospice & Palliative Medicine 2008;25(1):33-38.

20. Sato K, Miyashita M, Morita T, Sanjo M, Shima Y, Uchitomi Y. 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 Pall Med 2008;11:729-737.

21. van der Ploeg E, Depla MFI, Shekelle P, Rigter H, Mackenbach JP. Developing quality indicators for general practice care for vulnerable elders; transfer from US to The Netherlands. Qual Saf Health Care 2008;17(4):291-295.

22. Lorenz KA, Dy SM, Naeim A, Walling AM, Sanati H, Smith P, Shanman R, Roth CP, Asch SM. Quality measures for supportive cancer care: the Cancer Quality-ASSIST Project. J Pain Symptom Manage 2009;37(6):943-964.

23. Dy SM, Lorenz KA, O'Neill SM, Asch SM, Walling AM, Tisnado D, Antonio AL, Malin JL. Cancer Quality-ASSIST supportive oncology quality indicator set: feasibility, reliability, and validity testing. Cancer 2010;116(13):3267-3275.

24. Eagar K, Watters P, Currow DC, Aoun SM, Yates P. 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.
25. Schenck AP, Rokoske FS, Durham DD, Cagle JG, Hanson LC. The PEACE Project: identification of quality measures for hospice and palliative care. J Palliat Med 2010;13(12):1451-1459.

26. Department of Health. End of Life Care Strategy: Quality Markers and measures for end of life care. 2009 Available from http://webarchive.nationalarchives.gov.uk/20130107105354/http://www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsPolicyAndGuidance/DH_101681. Accessed 19th December 2014.

27. National Health Service. End of Life Care Quality Assessment (ELCQuA). 2011. Available from http://www.elcqua.nhs.uk/. Accessed 19th December 2014.

28. Palliative Care Outcomes Collaboration (PCOC). National Benchmarks and Targets. 2009. Available from https://ahsri.uow.edu.au/pcoc/benchmarkmeasures/index.html. Accessed 19th December 2014.

29. Brandt HE, Francke AL, Pasman HRW, Claessen SJJ, van der Putten MJA, Deliens L. Indicatoren voor Palliatieve Zorg: Ontwikkeling en toetsing van een set kwaliteitsindicatoren voor de palliatieve zorgverlening. [Quality indicators for palliative care: development and testing of a set of quality indicators for palliative care]. [In Dutch]. Utrecht: NIVEL, 2009. Available from http://www.nivel.nl/sites/default/files/bestanden/rapport-indicatoren-palliatieve-zorg.pdf. Accessed 19th December 2014.

30. Assessing care of vulnerable elders-3 quality indicators. J Am Geriatr Soc 2007;55(Suppl 2):S464-S487.

31. Clarke EB, Curtis JR, Luce JM, Levy M, Danis M, Nelson J, Solomon MZ. Quality indicators for end-of-life care in the intensive care unit. Crit Care Med 2003;31(9):2255-2262.

32. Earle CC, Park ER, Lai B, Weeks JC, Ayanian JZ, Block S. Identifying potential indicators of the quality of end-of-life cancer care from administrative data. J Clin Oncol 2003;21(6):1133-1138.

33. Earle CC, Neville BA, Landrum MB, Souza JM, Weeks JC, Block SD, Grunfeld E, Ayanian JZ. Evaluating claims-based indicators of the intensity of end-of-life cancer care. Int J Qual Health Care 2005;17(6):505-509.

34. Grunfeld E, Lethbridge L, Dewar R, Lawson B, Paszat LF, Johnston G, Burge F, McIntyre P, Earle CC. 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.

35. 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;42(8):853-860.

36. Lorenz K, Lynn K. Cancer care quality measures: Symptoms and end-of-life care. Evidence Report/Technology Assessment No. 137 (Prepared by the Southern California Evidence-based Practice Center under Contract No. 290-02-003). AHRQ Publications No. 06-E001. Rockville, MD: Agency for Healthcare Research and Quality, 2006.

37. Lorenz KA, Lynn J, Dy S, Wilkinson A, Mularski RA, Shugarman LR, Hughes R, Asch SM, Rolon C, Rastegar A, Shekelle PG. Quality measures for symptoms and advance care planning in cancer: a systematic review. J Clin Oncol 2006;24(30):4933-4938.

38. 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.

39. Mularski RA, Curtis JR, Billings JA, Burt R, Byock I, Fuhrman C, Mosenthal AC, Medina J, Ray DE, Rubenfeld GD, Schneiderman LJ, Treece PD, Truog RD, Levy MM. Proposed quality measures for palliative care in the critically ill: a consensus from the Robert Wood Johnson Foundation Critical Care Workgroup. Crit Care Med 2006;34(11 Suppl):S404-S411.

40. Nelson JE, Mulkerin CM, Adams LL, Pronovost PJ. Improving comfort and communication in the ICU: a practical new tool for palliative care performance measurement and feedback. Qual Saf Health Care 2006;15(4):264-271.

41. Peruselli C, Marinari M, Brivio B, Castagnini G, Cavana M, Centrone G, Magni C, Merlini M, Scaccabarozzi GL, Paci E. Evaluating a home palliative care service: development of indicators for a continuous quality improvement program. J Palliat Care 1997;13(3):34-42.

42. Saliba D, Solomon D, Rubenstein L, Young R, Schnelle J, Roth C, Wenger N. Feasibility of quality indicators for the management of geriatric syndromes in nursing home residents. J Am Med Dir Assoc 2004;5(5):310-319.

43. Shekelle PG, MacLean CH, Morton SC, Wenger NS. Assessing care of vulnerable elders: methods for developing quality indicators. Ann Intern Med 2001;135(8 Pt 2):647-52.

44. Teno JM, Casey VA, Welch LC, Edgman-Levitan S. Patient-focused, family-centered end-of-life medical care: views of the guidelines and bereaved family members. J Pain Symptom Manage 2001;22(3):738-751.

45. Teno JM, Clarridge B, Casey V, Edgman-Levitan S, Fowler J. Validation of Toolkit After-Death Bereaved Family Member Interview. J Pain Symptom Manage 2001;22(3):752-758.

46. Twaddle ML, Maxwell TL, Cassel JB, Liao S, Coyne PJ, Usher BM, Amin A, Cuny J. Palliative care benchmarks from academic medical centers. J Palliat Med 2007;10(1):86-98.

47. Wenger NS, Rosenfeld K. Quality indicators for end-of-life care in vulnerable elders. Ann Intern Med 2001;135(8 Pt 2):677-685.

48. Wenger NS, Solomon DH, Roth CP, MacLean CH, Saliba D, Kamberg CJ, Rubenstein LZ, Young RT, Sloss EM, Louie R, Adams J, Chang JT, Venus PJ, Schnelle JF, Shekelle PG. The quality of medical care provided to vulnerable community-dwelling older patients. Ann Intern Med 2003;139(9):740-747.

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

50. National Quality Forum. National voluntary consensus standards for symptom management and end-of-life care in cancer patients. 2006. Available from http://www.qualityforum.org/. Accessed 19th December 2014.

51. Brook RH, McGlynn EA, Cleary PD. Quality of health care. Part 2: measuring quality of care. N Engl J Med 1996;335(13):966-970.

52. Mainz J. Defining and classifying clinical indicators for quality improvement. Int J Qual Health Care 2003;15(6):523-530.

53. Seow H, Snyder CF, Mularski RA, Shugarman LR, Kutner JS, Lorenz KA, Wu AW, Dy SM. A framework for assessing quality indicators for cancer care at the end of life. J Pain Symptom Manage 2009;38(6):903-912.

54. Brook RH, McGlynn EA, Shekelle PG. Defining and measuring quality of care: a perspective from US researchers. Int J Qual Health Care 2000;12(4):281-295.

55. Donabedian A. Quality assurance. Structure, process and outcome. Nurs Stand 1992;7(11 Suppl QA):4-5.

56. Donaldson MS, Field MJ. Measuring quality of care at the end of life. Arch Intern Med 1998;158(2):121-128.

57. Stewart AL, Teno J, Patrick DL, Lynn J. The concept of quality of life of dying persons in the context of health care. J Pain Symptom Manage 1999;17(2):93-108.

58. Steel N, Melzer D, Shekelle PG, Wenger NS, Forsyth D, McWilliams BC. Developing quality indicators for older adults: transfer from the USA to the UK is feasible. Qual Saf Health Care 2004;13(4):260-264.

59. Marshall MN, Shekelle PG, McGlynn EA, Campbell S, Brook RH, Roland MO. Can health care quality indicators be transferred between countries? Qual Saf Health Care 2003;12(1):8-12.

## APPENDIX 1 – SEARCH STRATEGY PUBMED/MEDLINE

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

## APPENDIX 2 – CATEGORIES AND ITEMS OF THE AIRE INSTRUMENT

**1) Stakeholder involvement**

Item 1.1 The group developing the indicator includes individuals from relevant professional groups

Item 1.2 Considering the purpose of the indicator, all relevant stakeholders have been involved at some stage of the development process

Item 1.3 The indicator has been formally endorsed

**2) Scientific evidence**

Item 2.1 Systematic methods were used to search for scientific evidence

Item 2.2 The indicator is based on recommendations from an evidence-based guideline

Item 2.3 The supporting evidence has been critically appraised

**3) Additional evidence, formulation and usage**

Item 3.1 The numerator and denominator are described in detail

Item 3.2 The target patient population of the indicator is defined clearly

Item 3.3 A strategy for risk adjustment has been considered and described

Item 3.4 The indicator measures what it is intended to measure (validity)

Item 3.5 The indicator measures accurately and consistently (reliability)

Item 3.6 The indicator has sufficient discriminative power

Item 3.7 The indicator has been piloted in practice

Item 3.8 The efforts needed for data collection have been considered

Item 3.9 Specific instructions for presenting and interpreting the indicator results are provided

AIRE= Appraisal of Indicators through Research and Evaluation (AIRE) Instrument. Available from: http://www.ha-ring.nl/download/literatuur/Handleiding%20Indicatorenontwikkeling%20CBO.pdf.

The complete AIRE Instrument contains a fourth category 'purpose, relevance and organizational context', which is not used in this review.

# APPENDIX 3 –QUALITY INDICATORS FOR PALLIATIVE CARE PER DOMAIN

| **Domain 1.1: Structure of care (33 indicators)** | | | |
|---|---|---|---|
| | **Reference/ year** | **Description/type of indicator** | **Numerator/Denominator/Exclusion/ Performance standard** |
| 1 | Mularski, 2006 | Documentation of a policy that allows for unrestricted visitation by family members and friends.<br>Structure | **Numerator**: Presence of a policy in the ICU that allows for family and friends to spend time in the patient's room regardless of the time of the day. Policy may include restrictions on the number of visitors at one time or restrictions based on disturbance of other patients or family members or disturbance of the functioning of the ICU. Policies may also include provisions for asking family members or friends to wait in the waiting room during procedures<br>**Denominator**: ICU<br>**Exclusion**: -<br>**Performance standard**: - |
| 2 | Nelson, 2006 | Family meeting room: dedicated space for meetings between clinicians and ICU families.<br>Structure | Periodic point measurement: presence or absence of room designated for family meetings.<br>**Numerator**: -<br>**Denominator**: -<br>**Exclusion**: -<br>**Performance standard**: - |
| 3 | NEW ELCQuA, 2011 | Families and carers can access designated quiet spaces, and are able to view the deceased in appropriate surroundings.<br>Structure | **Numerator:** Number of wards with designated quiet area per organisation<br>**Denominator:** Total number of wards per organisation<br>**Exclusion**: -<br>**Performance standard**: 100% |
| 4 | Mularski, 2006 | Documentation of a forum for ICU clinicians to review, to discuss, and to debrief the experience of caring for dying patients and their families.<br>Structure | **Numerator**: Presence of a forum for ICU clinicians to review, discuss, and debrief the experience of caring for dying patients and their families<br>**Denominator**: ICU<br>**Exclusion**: -<br>**Performance standard**: - |
| 5 | Peruselli, 1997 | Palliative care service is integrated into the local area health authority and operates at the specific request of the GP and in association with him/her.<br>Process | **Numerator**: Number of patients for whom the PCS have had the introductory interview with GP concerning the program objectives<br>**Denominator**: Population served x 100<br>**Exclusion**: -<br>**Performance standard**: 95% |
| 6 | Peruselli, 1997 | Palliative care service is integrated into the local area health authority and operates at the specific request of the GP and in association with him/her.<br>Process | **Numerator**: Number of GPs who have requested the PCS<br>**Denominator**: Total number of GPs in area of health care authority x 100<br>**Exclusion**: -<br>**Performance standard**: 50% |

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| 7 | Peruselli, 1997 | Palliative care service is integrated into the local area health authority and operates at the specific request of the GP and in association with him/her.<br>Process | **Numerator**: Number of patients for whom the PCS had have at least 2 interviews with the GP during care process (including preliminary discussion)<br>**Denominator**: Population served<br>**Exclusion**: -<br>**Performance standard**: 50% |
| 8 | $^{NEW}$ Quality Markers, 2009<br>$^{NEW}$ ELCQuA, 2011 | QM for commissioners: Availability of services: There is appropriate provision of specialist palliative care services to meet the needs of the population: inpatient services (e.g. specialist palliative care).<br>Structure | **Numerator:** Numbers of specialist palliative care beds available<br>**Denominator:** Per 100,000 patients<br>**Exclusion**: -<br>**Performance standard:** - |
| 9 | Peruselli, 1997 | Home palliative care services reduce admissions to hospital during care period.<br>Process | **Numerator**: Number of days in hospital during HPC<br>**Denominator**: Total number of days of HPC care x 100<br>**Exclusion**: -<br>**Performance standard**: 10% |
| 10 | Peruselli, 1997 | The palliative care service responds rapidly to request for care.<br>Process | **Numerator**: Number of patients who received initial visits from a team member within 48 hours of request<br>**Denominator**: Population served x 100<br>**Exclusion**: -<br>**Performance standard**: 95% |
| 11 | Peruselli, 1997 | Palliative care services are devised for terminal patients during the final stages of life.<br>Process | **Numerator**: Number of patients receiving home care for 7 to 90 days<br>**Denominator**: Population served x 100<br>**Exclusion**: -<br>**Performance standard**: 75% |
| 12 | Peruselli, 1997 | Home palliative care enables patients to stay at home until death.<br>Process | **Numerator**: Number of patients dying at home<br>**Denominator**: Total patients x 100<br>**Exclusion**: -<br>**Performance standard**: 95% |
| 13 | Earle, 2006 | Proportion dying in an acute care setting.<br>Process | **Numerator**: Patients who died from cancer in an acute care hospital<br>**Denominator**: Patients who died from cancer<br>**Exclusion**: -<br>**Performance standard**: <17% |
| 14 | Earle, 2006 | Proportion not admitted to hospice.<br>Process | **Numerator**: Patients who died from cancer without being admitted to hospice<br>**Denominator**: Patients who died from cancer<br>**Exclusion**: -<br>**Performance standard**: <45% |
| 15 | Earle, 2006 | Proportion admitted to hospice for less than 3 days.<br>Process | **Numerator**: Patients who died from cancer and spent fewer than three days in hospice<br>**Denominator**: Patients who died from cancer who were admitted to hospice<br>**Exclusion**: -<br>**Performance standard**: <8% |

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| 16 | NEW Grunfeld, 2008 | Access to care<br>Fair and equitable access to care for patient and family, regardless of financial considerations, indicates good quality care. A high proportion may indicate poor quality care.<br>Outcome | **Numerator:** Number of cases living in a rural area<br>**Denominator:** Entire cohort<br>**Exclusion**: -<br>**Performance standard**: - |
| 17 | NEW Grunfeld, 2008 | Access to palliative care<br>Palliative care will be accessible to all patients and families with a cancer diagnosis, in a timely manner, throughout the entire duration of their disease. A high proportion may indicate good quality care.<br>Outcome | **Numerator:** Number of cases enrolled in palliative care<br>**Denominator:** All cases<br>**Exclusion**: -<br>**Performance standard**: - |
| 18 | NEW Quality Markers, 2009 | QM for commissioners: Availability of services: Essential services are available and accessible in the community 24/7 for all who need them to enable people to live and die in the place of their choice.<br>Structure | Proportion of the local population covered by these services<br>**Numerator**: -<br>**Denominator**: -<br>**Exclusion**: -<br>**Performance standard**: - |
| 19 | NEW Quality Markers, 2009 | QM for commissioners: Availability of services: People approaching the end of life in care homes have the same level of access to specialist care services as for those who live at home.<br>Structure | Proportion of deceased individuals who received specialist palliative care services<br>**Numerator**: -<br>**Denominator**: -<br>**Exclusion**: -<br>**Performance standard**: - |
| 20 | NEW Quality Markers, 2009 | QM for district/community nursing services.<br>They have practical arrangements in place to support those dying at home or in care home.<br>Structure | Proportion of cases with equipment, supplies and crisis boxes in place and out of hours sitting services available<br>**Numerator**: -<br>**Denominator**: -<br>**Exclusion**: -<br>**Performance standard**: - |

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| 21 | NEW Eagar, 2010 | Time from referral to first contact<br>Time from referral to first contact is calculated as the time in days between the referral date and the date of first contact or episode start date (whichever occurs first) and is calculated for all episodes of care and across all settings of care.<br>Structure | **Numerator/Denominator:** Percentage of patients that are contacted by a member of the clinical team (either face to face or by phone) within 48 hours of referral (including weekends)<br>**Exclusion**: -<br>**Performance standard:** 90% |
| 22 | NEW ELCQuA, 2011 | People can access specialist palliative care as needed, regardless of diagnosis or location.<br>Structure | **Numerator:** Number of specialist palliative care consultants<br>**Denominator:** 100,000 population<br>**Exclusion**: -<br>**Performance standard**: -<br>(Other measurement option: see Indicator 8) |
| 23 | NEW Quality Markers, 2009 | QM for commissioners: Co-ordination of care across organisational boundaries: A locality-wide register of individuals approaching the end of life is maintained.<br>Structure | Proportion of deceased individuals who entered onto the locality-wide register<br>**Numerator**: -<br>**Denominator**: -<br>**Exclusion**: -<br>**Performance standard**: - |
| 24 | NEW Quality Markers, 2009 | QM for commissioners: Monitoring: Primary Care Trusts must: Individual organisations monitor the quality and outputs of end of life care and submit relevant information to local and national audits.<br>Structure | Proportion of general practices which provide data in line with local agreements<br>**Numerator**: -<br>**Denominator**: -<br>**Exclusion**: -<br>**Performance standard**: - |
| 25 | NEW Quality Markers, 2009 | QM for commissioners: Monitoring: Primary Care Trusts must: Individual organisations monitor the quality and outputs of end of life care and submit relevant information to local and national audits.<br>Structure | Proportion of care homes which provide data in line with local agreements<br>**Numerator**: -<br>**Denominator**: -<br>**Exclusion**: -<br>**Performance standard**: - |

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| 26 | NEW Quality Markers, 2009 | QM for commissioners: Monitoring: Primary Care Trusts must: Individual organisations monitor the quality and outputs of end of life care and submit relevant information to local and national audits.<br>Structure | Proportion of hospitals which provide data in line with local agreements<br>**Numerator**: -<br>**Denominator**: -<br>**Exclusion**: -<br>**Performance standard**: - |
| 27 | NEW Quality Markers, 2009 | QM for commissioners: Monitoring: Primary Care Trusts must: Individual organisations monitor the quality and outputs of end of life care and submit relevant information to local and national audits.<br>Structure | Proportion of specialist palliative care inpatient facilities (e.g. hospices) which provide data in line with local agreements<br>**Numerator**: -<br>**Denominator**: -<br>**Exclusion**: -<br>**Performance standard**: - |
| 28 | NEW Quality Markers, 2009 | QM for commissioners: Monitoring: Primary Care Trusts must: Individual organisations monitor the quality and outputs of end of life care and submit relevant information to local and national audits.<br>Structure | Proportion of community palliative care teams which provide data in line with local agreements<br>**Numerator**: -<br>**Denominator**: -<br>**Exclusion**: -<br>**Performance standard**: - |
| 29 | NEW Quality Markers, 2009 | QM for acute hospitals: They ensure that relevant information on patients approaching the end of life is entered into a locality-wide register (where available) or otherwise communicated to other health and social care professionals involved in the patient's care.<br>Structure | Proportion of deceased patients who were recorded in the locality-wide register (locality-wide registers for end of life care are to be piloted starting in 2009)<br>**Numerator**: -<br>**Denominator**: -<br>**Exclusion**: -<br>**Performance standard**: - |
| 30 | NEW ELCQuA, 2011<br>This indicator suits domain 1 and 8. | People approaching the end of life are identified.<br>Process | **Numerator:** Number of deaths on register OR with identified advance care plan<br>**Denominator:** Total deaths for same catchment and time period<br>**Exclusion:** -<br>**Performance standard:** -<br>**Numerator:** Non-cancer deaths on register OR with an advance care plan identified<br>**Denominator:** Non-cancer deaths for same catchment for same time period<br>**Exclusion:** -<br>**Performance standard:** - |

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| 31 | NEW Quality Markers, 2009 | QM for acute hospitals: They have processes in place to identify the training needs of all workers (registered and unregistered) in the hospital that take into account the four core common requirements for workforce development (communication skills, assessment and care planning, advance care planning, and symptom management) as they apply to end of life care.<br>Structure | Proportion of workers attending educational programs related to end of life care for registered workers<br>**Numerator**: -<br>**Denominator**: -<br>**Exclusion**: -<br>**Performance standard**: - |
| 32 | NEW Quality Markers, 2009 | QM for acute hospitals: They have processes in place to identify the training needs of all workers (registered and unregistered) in the hospital that take into account the four core common requirements for workforce development (communication skills, assessment and care planning, advance care planning, and symptom management) as they apply to end of life care.<br>Structure | Proportion of workers attending "foundation" programs in end of life care for non-registered workers who may have to deal with patients approaching the end of life or just after death, or their families and carers<br>**Numerator**: -<br>**Denominator**: -<br>**Exclusion**: -<br>**Performance standard**: - |
| 33 | NEW Quality Markers, 2009 | QM for acute hospitals: They (acute hospital providers) have effective mechanisms for identifying those who are at the end of life.<br>Structure | Proportion of front-line clinicians who have undergone formal training<br>**Numerator**: -<br>**Denominator**: -<br>**Exclusion**: -<br>**Performance standard**: - |
| **Domain 1.2: Process of care (62 indicators)** | | | |
| | **Reference/ year** | **Description/type of indicator** | **Numerator/Denominator/Exclusion/ Performance standard** |
| 34 | Mularski, 2006 | Documentation of communication between a physician and a family member or friend of the patient within 24 hours of admission.<br>Process | **Numerator**: Patients in the ICU for > 24 hours for whom there is documentation that a physician communicated with a family member or friend of the patient in person or by phone<br>**Denominator**: Total number of patients in the ICU for > 24 hours for whom a family member or friend can be identified<br>**Exclusion**: Patient for whom no family member or friend can be identified in the first 24 hours<br>**Performance standard**: - |

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| 35 | Nelson, 2006,<br>Mularski, 2006 | Interdisciplinary family meeting:<br>Percentage of patients with documentation that an interdisciplinary family meeting was conducted on or before day 5 of ICU admission.<br>Process | **Numerator**: Number of patients who have documentation in the medical record that an interdisciplinary meeting was held with the patient/family on or before day 5 of ICU admission<br>**Denominator**: Total number of patient with an ICU length of stay<br>**Exclusion:** ≥ 5 days<br>Patients who were not visited by a family member on or before day 5 of ICU admission AND who lack capacity to participate in such a meeting<br>Patients who refused or whose family refused to participate in a family meeting<br>**Performance standard**: - |
| 36 | Nelson, 2006 | Family information leaflet:<br>Percentage of patients whose families received information leaflet (personally) from ICU team member on or before day 1 of ICU admission and action was documented in the medical record.<br>Process | **Numerator:** Number of patients with documentation that family received a written information leaflet from an ICU team member<br>**Denominator:** Total number of patients with an ICU length of stay > 5 days<br>**Exclusion:** Patients discharged (or transferred out of the ICU) on or before day 1 of ICU admission<br>Patients expired on or before day 1 of ICU admission<br>Patients who were not visited by a family member on or before day 1 of ICU admission<br>**Performance standard:** - |
| 37 | Yabroff, 2004 | Percentage of patients and family/caregivers within health facilities or systems that understand and are satisfied with provider communication about prognosis.<br>Outcome | **Numerator**: -<br>**Denominator**: -<br>**Exclusion**: -<br>**Performance standard**: - |
| 38 | Yabroff, 2004 | Percentage of patients and family/caregivers within and among health facilities or systems that understand and are satisfied with provider communication about risks and benefits or treatment.<br>Outcome | **Numerator**: -<br>**Denominator**: -<br>**Exclusion**: -<br>**Performance standard**: - |
| 39 | Yabroff, 2004 | Percentage of patients within and among health facilities or systems where evidence exists to confirm accurate communication about prognosis.<br>Process | **Numerator**: -<br>**Denominator**: -<br>**Exclusion**: -<br>**Performance standard**: - |

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| 40 | Yabroff, 2004 | Percentage of patients within and among health facilities or systems where evidence exists to confirm accurate communication about risks and benefits of treatment.<br>Process | **Numerator**: -<br>**Denominator**: -<br>**Exclusion**: -<br>**Performance standard**: - |
| 41 | Yabroff, 2004 | Percentage of patients and family/caregivers within and among health facilities or systems that understand and are satisfied with their participation in the development of treatment goals.<br>Outcome | **Numerator**: -<br>**Denominator**: -<br>**Exclusion**: -<br>**Performance standard**: - |
| 42 | Peruselli, 1997 | Palliative care services must meet the physical, psychological, social and spiritual needs of patients.<br>Outcome | **Numerator**: Number of patients with score for patient insight (STAS item) dropped after 8 days of care (if initial score >0)<br>**Denominator**: Total patients x 100<br>**Exclusion**: -<br>**Performance standard**: 75% |
| 43 | Peruselli, 1997 | Palliative care services must meet the physical, psychological, social and spiritual needs of patients.<br>Outcome | **Numerator**: Number of patients with score for patient insight (STAS item) of 0-1 during final week of life<br>**Denominator**: Total patients x 100<br>**Exclusion**: -<br>**Performance standard**: 75% |
| 44 | Peruselli, 1997 | Palliative care services must meet the physical, psychological, social and spiritual needs of patients.<br>Outcome | **Numerator**: Number of patients with score for family insight (STAS item) dropped after 8 days of care (if initial score >0)<br>**Denominator**: Total patients x 100<br>**Exclusion**: -<br>**Performance standard**: 75% |
| 45 | Peruselli, 1997 | Palliative care services must meet the physical, psychological, social and spiritual needs of patients.<br>Outcome | **Numerator**: Number of patients with score for family insight (STAS item) of 0-1 during final week of life<br>**Denominator**: Total patients x 100<br>**Exclusion**: -<br>**Performance standard**: 75% |
| 46 | Peruselli, 1997 | Home palliative care services are the result of a joint decision taken by the care team and family.<br>Process | **Numerator**: Number of patients for whom the PCS had preliminary interview at the outpatient clinic together with the family<br>**Denominator**: Population served x 100<br>**Exclusion**: -<br>**Performance standard**: 95% |
| 47 | Peruselli, 1997 | Palliative care services must meet the physical, psychological, social and spiritual needs of patients.<br>Outcome | **Numerator**: Number of patients with score for communication between professionals (STAS item) dropped after 8 days of care (if initial score >0)<br>**Denominator**: Total patients x 100<br>**Exclusion**: -<br>**Performance standard**: 75% |

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| 48 | Peruselli, 1997 | Palliative care services must meet the physical, psychological, social and spiritual needs of patients.<br>Outcome | **Numerator**: Number of patients with score for communication between professionals (STAS item) of 0-1 during final week of life<br>**Denominator**: Total patients x 100<br>**Exclusion**: -<br>**Performance standard**: 75% |
| 49 | Peruselli, 1997 | Palliative care services must meet the physical, psychological, social and spiritual needs of patients.<br>Outcome | **Numerator**: Number of patients with score for communication professional to patient and family (STAS item) dropped after 8 days of care (if initial score >0)<br>**Denominator**: Total patients x 100<br>**Exclusion**: -<br>**Performance standard**: 75% |
| 50 | Peruselli, 1997 | Palliative care services must meet the physical, psychological, social and spiritual needs of patients.<br>Outcome | **Numerator**: Number of patients with score for communication professional to patient and family (STAS item) of 0-1 during final week of life<br>**Denominator**: Total patients x 100<br>**Exclusion**: -<br>**Performance standard**: 75% |
| 51 | $^{\text{NEW}}$ Miyashita, 2008 (omitted in Sato, 2008) | Decision making and preference of care: Discussion of strategy of care among physicians and nurses.<br>Process | **Numerator:** Number of patients for whom this indicator was documented on admission or within the last 2 weeks of the hospitalization<br>**Denominator:** All patients who died (retrospectively identified)<br>**Exclusion: -**<br>**Performance standard: -** |
| 52 | $^{\text{NEW}}$ Miyashita, 2008 (and split up in 2 separate indicators, one for patient and one for family by Sato, 2008) | Decision making and preference of care: Explanation of medical condition to patient.<br>Process | **Numerator:** Number of patients for whom this indicator was documented on admission or within the last 2 weeks of the hospitalization<br>**Denominator:** All patients who died (retrospectively identified)<br>**Exclusion: -**<br>**Performance standard: -** |
| 53 | $^{\text{NEW}}$ Miyashita, 2008 (and split up in 2 separate indicators, one for patient and one for family by Sato, 2008) | Family care: Explanation of medical condition to family.<br>Process | **Numerator:** Number of patients for whom this indicator was documented on admission or within the last 2 weeks of the hospitalization<br>**Denominator:** All patients who died (retrospectively identified)<br>**Exclusion: -**<br>**Performance standard: -** |
| 54 | $^{\text{NEW}}$ Miyashita, 2008 | Family care: Explanation to family about course of disease until death.<br>Process | **Numerator:** Number of patients for whom this indicator was documented on admission or within the last 2 weeks of the hospitalization<br>**Denominator:** All patients who died (retrospectively identified)<br>**Exclusion: -**<br>**Performance standard: -** |
| 55 | $^{\text{NEW}}$ Miyashita, 2008 ; Sato, 2008 | Family care: Explanation to family of patient's impending death.<br>Process | **Numerator:** Number of patients for whom this indicator was documented on admission or within the last 2 weeks of the hospitalization<br>**Denominator:** All patients who died (retrospectively identified)<br>**Exclusion: -**<br>**Performance standard: -** |

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| 56 | NEW Miyashita, 2008 | Family care: Explanation to family 1 week prior to patient's death.<br>Process | **Numerator:** Number of patients for whom this indicator was documented on admission or within the last 2 weeks of the hospitalization<br>**Denominator:** All patients who died (retrospectively identified)<br>**Exclusion: -**<br>**Performance standard: -** |
| 57 | NEW Grunfeld, 2008 | Multidisciplinary care<br>Multidisciplinary care is considered an element of quality cancer care as it provides patients with access to practitioners with different perspectives and skill sets in order to achieve holistic care. Examples may include nursing services, social work, specialised medical services. A high proportion may indicate poor quality care.<br>Process | **Numerator:** Sum of GP visits for the entire cohort<br>**Denominator:** Sum of physician visits for the entire cohort<br>**Exclusion: -**<br>**Performance standard: -**<br>**Numerator:** Sum of non-GP visits for the entire cohort<br>**Denominator:** Sum of physician visits for the entire cohort<br>**Exclusion: -**<br>**Performance standard: -** |
| 58 | NEW Quality Markers, 2009 | QM for primary care:<br>They discuss and record the needs of those approaching the end of life at multi-disciplinary team meetings, preferably monthly but a minimum quarterly (refer to the Quality and Outcomes Framework).<br>Process | Audits of the proportion of deceased individuals who were discussed at a practice-level multidisciplinary meeting in the last year of their lives (this will need to take account of the fact that not all deaths are predictable)<br>**Numerator:** -<br>**Denominator:** -<br>**Exclusion: -**<br>**Performance standard: -** |
| 59 | NEW Lorenz, 2009 | Information and care planning IF a patient with cancer undergoes chemotherapy, THEN before chemotherapy, s/he should be informed about the risks and benefits of treatment, including likely symptoms and side effects, and whether the treatment intent is curative or palliative.<br>Process | **Numerator: -**<br>**Denominator:** -<br>**Exclusion:** -<br>**Performance standard:** - |
| 60 | NEW ELCQuA, 2011 | People benefit from multi-disciplinary specialist palliative care team input into their care.<br>Process | **Numerator:** Number of people on palliative care register discussed in MDM<br>**Denominator:** Number of people on palliative care register<br>**Exclusion:** -<br>**Performance standard:** - |

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| 61 | Twaddle, 2007 | Documentation of patient status<br>Percentage of all patients with documentation of prognosis, psychosocial symptoms, functional status, and overall symptom distress within 48 hours of admission.<br>Process | **Numerator**: -<br>**Denominator**: -<br>**Exclusion**: -<br>**Performance standard**: 90% |
| 62 | Lorenz, 2007 | Comprehensive palliative assessment<br>IF a VE dies an expected death with metastatic cancer, oxygen-dependent pulmonary disease, New York Heart Association (NYHA) Class III to IV congestive heart failure (CHF), end-stage (stage IV) renal disease, or dementia, THEN the chart should document pain and other symptoms, spiritual and existential concerns, caregiver burdens and needs for practical assistance, and advance care planning (ACP) within 6 months before death, BECAUSE these concerns are known to be important to patients with advanced illnesses as part of their late-life care.<br>Process | **Numerator**: -<br>**Denominator**: -<br>**Exclusion**: -<br>**Performance standard**: - |
| 63 | NEW Schenck, 2010 | Structure and Process: Percent of patients who have screening for physical and psychological symptoms during the admission visit.<br>Process | **Numerator:** Number of patients with all times=0<br>(Pain Time=Pain screening date-date of admission<br>Dyspnea Time= Dyspnea screening date-date of admission<br>Nausea Time= Nausea screening date-date of admission<br>Constipation Time= Constipation screening date-date of admission<br>Depression Time= Depression screening date-date of admission<br>Anxiety Time= Anxiety screening date-date of admission)<br>**Denominator:** Total # of patients<br>**Exclusion: -**<br>**Performance standard: -** |

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| 64 | NEW Schenck, 2010 | Structure and Process: Percent of patients who have comprehensive assessment completed within 5 days of admission.<br>Process | **Numerator:** Number of patients with all times<=5<br>**Denominator:** Total # of patients<br>(Prognosis Time= Prognosis date-date of admission<br>(Note: if Prognosis Time < 0, set = 0)<br>Functional Status Time= Functional status screening date-date of admission<br>Pain Time=Pain screening date-date of admission<br>Dyspnea Time= Dyspnea screening date-date of admission<br>Nausea Time= Nausea screening date-date of admission<br>Constipation Time= Constipation screening date-date of admission<br>Depression Time= Depression screening date-date of admission<br>Anxiety Time= Anxiety screening date-date of admission<br>Spiritual Time= Spiritual discussion date-date of admission<br>Social Family Time= Family discussion date-date of admission)<br>**Exclusion: -**<br>**Performance standard: -** |
| 65 | Yabroff, 2004 | Percentage of patients within and among health facilities or systems with evidence that care plan was implemented by all providers consistent with goals of care.<br>Outcome | **Numerator**: -<br>**Denominator**: -<br>**Exclusion**: -<br>**Performance standard**: - |
| 66 | Yabroff, 2004 | Percentage of patients within and among health facilities or systems with evidence of care planning and provider-provider communication consistent with goals of care.<br>Process | **Numerator**: -<br>**Denominator**: -<br>**Exclusion**: -<br>**Performance standard**: - |
| 67 | Mularski, 2006 | Documentation that the goals of care and resuscitation status are communicated to the receiving team on transfer of the patient out of the ICU.<br>Process | **Numerator**: Total number of patients transferred out of the ICU with documentation that the goals of care and resuscitation status were communicated to the receiving team<br>**Denominator**: Total number of patients transferred out of the ICU alive to another service in the hospital or other care facility<br>**Exclusion**: Patients who die in the ICU and patients discharged to home from the ICU without home care services<br>**Performance standard**: - |

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| 68 | Mularski, 2006 | Documentation of the goals of care, in the patient chart, within 72 hours.<br>Process | **Numerator**: Total number of patients in the ICU for > 72 hours with documentation of the goals of care<br>**Denominator**: Total number of patients in the ICU for > 72 hours<br>**Exclusion**: -<br>**Performance standard**: - |
| 69 | Mularski, 2006 | Documentation of a policy that allows for continuity of nursing care for patients with multiple-day stay in the ICU for patients and family members.<br>Structure | **Numerator**: Presence of a policy in the ICU that supports arranging continuity of nurses for patients who spend > 1 day in the ICU<br>**Denominator**: ICU<br>**Exclusion**: -<br>**Performance standard**: - |
| 70 | Lorenz, 2007 | Advance directive and surrogate continuity<br>IF a VE has an advance directive in the outpatient, inpatient, or nursing home medical record, or the patient reports the existence of an advance directive in an interview, and the patient receives care in a second venue, THEN the advance directive should be present in the medical record at the second venue, or documentation should acknowledge its existence and its contents, BECAUSE an advance directive can guide care only if its existence is recognized and its content is known.<br>Process | **Numerator**: -<br>**Denominator**: -<br>**Exclusion**: -<br>**Performance standard**: - |
| 71 | NEW Quality Markers, 2009 | QM for commissioners: Care in the last days of life: All care providers adopt a common approach to care for people in the last days of life.<br>Process | Proportion of providers adopting a standardised approach (e.g. the Liverpool Care Pathway or equivalent)<br>**Numerator: -**<br>**Denominator: -**<br>**Exclusion: -**<br>**Performance standard: -** |
| 72 | NEW Quality Markers, 2009 | QM for commissioners: Care in the days after death: All providers have appropriate processes in place for verification and certification of death, including viewing of the body and return of personal property.<br>Process | Proportion of providers using the care after death module of the Liverpool Care Pathway (or equivalent)<br>**Numerator: -**<br>**Denominator: -**<br>**Exclusion: -**<br>**Performance standard: -** |

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| 73 | NEW Quality Markers, 2009 | QM for commissioners: Care in the days after death: All providers have appropriate processes in place for verification and certification of death, including viewing of the body and return of personal property.<br>Process | Proportion of individuals for whom the care after death module of the Liverpool Care Pathway (or equivalent) was used (including those who died suddenly)<br>**Numerator: -**<br>**Denominator: -**<br>**Exclusion: -**<br>**Performance standard: -** |
| 74 | NEW Quality Markers, 2009 | QM for district/community nursing services.<br>They have mechanisms in place to assess and document the needs of those approaching the end of life (e.g. use of the Gold Standards Framework or equivalent), and to discuss, record and, (where appropriate) communicate the wishes and preferences of those approaching the end of life (advance care planning).<br>Process | Proportion of nursing services that have adopted an approach to end of life care management (e.g. the Gold Standards Framework or equivalent)<br>**Numerator: -**<br>**Denominator: -**<br>**Exclusion: -**<br>**Performance standard: -** |
| 75 | NEW ELCQuA, 2011 | Individuals' preferences and choices are documented and communicated and available at all times of day to all relevant professionals.<br>People's advance care plans are available to professionals 24 hours a day, to ensure they can respond to the wishes of individuals at all times including out of hours.<br>Ambulance services can routinely and quickly identify people who are known to be approaching the end of life and respect their preferences.<br>Process | **Numerator:** Number of people who died who were recorded on an electronic end of life care register or equivalent + number who declined to have their record uploaded<br>**Denominator:** Total deaths for same time period<br>**Exclusion:** -<br>**Performance standard:** All patients approaching the end of life offered entry onto locality register, including DNACPR wishes and preferred place of care/death |

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| 76 | NEW ELCQuA, 2011 | People are treated with dignity and respect and are supported by a common care pathway management approach in the last hours or days of life.<br>Process/Outcome | **Numerator:** Number of deaths with LCP or equivalent in place<br>**Denominator:** Total deaths for same time period<br>**Exclusion: -**<br>**Performance standard:** Implementation of LCP or equivalent across the organisation (100%)<br>**Numerator:** Completed and available LCP goals documentation fields (scored either as 'achieved' or 'variance') for a consecutive sample of end of life patients<br>**Denominator:** Number of available and applicable LCP goals documentation fields for consecutive sample of the same number of end of life patients<br>**Exclusion: -** |
| 77 | NEW Quality Markers, 2009 | QM for community hospitals:<br>They (all community hospitals which provide relevant services) nominate a key worker for each patient approaching the end of life if required.<br>Process | Audits of the proportion of patients approaching the end of life with a documented key worker<br>**Numerator: -**<br>**Denominator: -**<br>**Exclusion: -**<br>**Performance standard: -** |
| 78 | NEW Quality Markers, 2009 | QM for care homes:<br>All care home providers that provide services to people approaching the end of life (care homes need to consider end of life care from the point of view of residents who may have a year or more to live, rather than days or weeks). They nominate a key worker for each patient approaching the end of life if required.<br>Process | Audits of the proportion of patients approaching the end of life with a documented key worker<br>**Numerator: -**<br>**Denominator: -**<br>**Exclusion: -**<br>**Performance standard: -** |
| 79 | NEW Quality Markers, 2009 | QM for specialist palliative care inpatient facilities e.g. hospices:<br>They nominate a key worker for each patient approaching the end of life if required.<br>Process | Audits of the proportion of patients approaching the end of life with a documented key worker<br>**Numerator: -**<br>**Denominator: -**<br>**Exclusion: -**<br>**Performance standard: -** |
| 80 | NEW Quality Markers, 2009 | QM for district/community nursing services.<br>They nominate a key worker for each patient approaching the end of life if required.<br>Process | Audits of the proportion of patients approaching the end of life with a documented key worker<br>**Numerator: -**<br>**Denominator: -**<br>**Exclusion: -**<br>**Performance standard: -** |

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| 81 | $^{\text{NEW}}$ ELCQuA, 2011 | People are able to contact a dedicated key worker at all times.<br>Process | **Numerator:** Number of patients/service users who died with a documented key worker<br>**Denominator:** Total deaths for same time period<br>**Exclusion**: -<br>**Performance standard**: - |
| 82 | Yabroff, 2004 | Percentage of patients within and among health facilities or systems where evidence exists to confirm patient/family/caregiver participation in the discussion and development of their treatment goals.<br>Process | **Numerator**: -<br>**Denominator**:-<br>**Exclusion**: -<br>**Performance standard**: - |
| 83 | National Hospice and Palliative Care Organization (NHPCO), 2006<br>Brown University, 2006 | Provide coordination of care (Family evaluation of hospice care)<br>Questions:<br>F1: How often did someone from the hospice team give confusing or contradictory information about the patient's medical treatment?<br>F2: While under the care of hospice, was there always one nurse who was identified as being in charge of the patient's overall care?<br>F3: Was there any problem with hospice doctors or nurses not knowing enough about the patient's medical history to provide the best possible care?<br>Process | **Numerator**: Sum of 1 response to survey instrument by family member of deceased patient<br>**Denominator**: Number of items (=3)<br>**Exclusion**: Patients who are not enrolled in a hospice program or have disenrolled from a hospice program. Live discharged are excluded<br>**Performance standard**: - |
| 84 | Twaddle, 2007 | Patient/family meeting<br>Percentage of all cases with documentation that a patient/family meeting (i.e. meeting between patient/family and members of the health care team to discuss the patient's treatment preferences or the plans for discharge disposition) occurred during the first week of the hospital stay.<br>Process | **Numerator**: -<br>**Denominator**: -<br>**Exclusion**: -<br>**Performance standard**: 90% |

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| 85 | Peruselli, 1997 | Satisfaction for patients and families is crucial to palliative care services, which considers clients to be their central focus.<br>Outcome | **Numerator**: Number of responses to questionnaire items answered "excellent" by both patient and family<br>**Denominator**: Total number of responses x 100<br>**Exclusion**: -<br>**Performance standard**: 75% |
| 86 | Twaddle, 2007 | Documentation of discharge plan<br>Percentage of all patients with documentation of discharge plan (i.e. early documentation of statements such as 'likely to require health services at discharge' or 'not expected to survive this admission') within 4 days of admission.<br>Process | **Numerator**: -<br>**Denominator**: -<br>**Exclusion**: -<br>**Performance standard**: 90% |
| 87 | Twaddle, 2007 | Discharge planner arranged services required for discharge<br>Percentage of all cases with documentation that a discharge planner or other hospital personnel arranged any home services necessary.<br>Process | **Numerator**: -<br>**Denominator**: -<br>**Exclusion**: -<br>**Performance standard**: 90% |
| 88 | NEW Grunfeld, 2008 | Enrollment in palliative care within 6 months of death<br>A high proportion may indicate poor quality care. Palliative care should be accessible to all patients and families with a cancer diagnosis, in a timely manner, throughout the entire duration of their disease.<br>Process | **Numerator:** Number of cases enrolled in palliative care within six months prior to death<br>**Denominator:** All cases enrolled in palliative care<br>**Exclusion: -**<br>**Performance standard: -** |
| 89 | NEW Lorenz, 2009 | Information and care planning IF a patient with advanced cancer dies an expected death, THEN s/he should have been referred for palliative care before death (hospital-based or community hospice) OR there should be documentation why there was no referral.<br>Process | **Numerator**: -<br>**Denominator**: -<br>**Exclusion**: -<br>**Performance standard**: - |

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| 90 | NEW Claessen, 2011 | Generic aspects: Percentage of patients who receive medical aids soon enough<br>Receiving medical aids soon enough is an important quality aspect of palliative care.<br>Outcome | **Numerator:** The number of patients who indicate that they receive medical aids soon enough<br>**Denominator:** The total number of patients among whom this quality indicator was measured<br>**Exclusion:** Patients with moderate to (very) severe cognitive impairments, young children, and comatose and deeply sedated patients<br>**Performance standard: -** |
| 91 | NEW Eagar, 2010 | Time in the unstable phase<br>Time in the unstable phase is calculated as the difference between the phase start date and the phase end date and is analyzed by episode type and then occurrence of the unstable phase during the episode.<br>Outcome | Percentage of patients in their first palliative care phase remain in the unstable phase for less than 7 days<br>**Numerator**: -<br>**Denominator**: -<br>**Exclusion**: -<br>**Performance standard:** 85%<br>Percentage of patients in a subsequent palliative care phase who remain in the unstable phase for less than 7 days<br>**Numerator**: -<br>**Denominator**: -<br>**Exclusion**: -<br>**Performance standard:** 90% |
| 92 | NEW ELCQuA, 2011 | Care for individuals is coordinated across organisational boundaries 24 hours a day, seven days a week.<br>Outcome | **Numerator:** Number of emergency admissions for patients in last 12 months of life<br>**Denominator:** Total deaths for same time period<br>**Exclusion**: -<br>**Performance standard**: - |
| 93 | NEW ELCQuA, 2011 | People can be transferred quickly and sensitively to their preferred location of care.<br>Outcome | **Numerator:** Sum of delay (days) for EoL patients awaiting transfer from a) home, and b) acute sector to preferred location<br>**Denominator:** Total number of deaths where a transfer is requested<br>**Exclusion**: -<br>**Performance standard**: - |
| 94 | NEW ELCQuA, 2011 | Ambulances services inform GPs where they have transferred a person who is at the end of life to a hospital.<br>Process | **Numerator:** Number of transfers for people on EOLC register where the GP is informed<br>**Denominator:** Total number of transfers for people on EOLC register<br>**Exclusion**: -<br>**Performance standard**: - |
| 95 | NEW ELCQuA, 2011 | All organisations communicate effectively with people's GPs around end of life decisions and inform the general practice within 24 hours when a person dies.<br>Process | **Numerator:** Number of deaths where the GP is informed within 24 hours<br>**Denominator:** Total number of deaths<br>**Exclusion**: -<br>**Performance standard:** GPs receive timely notification of all deaths |

| Domain 2: Physical aspects of care (112 indicators) | | | |
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| | **Reference/ year** | **Description/type of indicator** | **Numerator/Denominator/Exclusion/ Performance standard** |
| 96 | Keay, 1994 | If a patient had pain, this is followed to assess results of intervention and pain is reduced.<br>Process/Outcome | **Numerator: -**<br>**Denominator:-**<br>**Exclusion:** Intractable pain ever after consultation<br>**Performance standard: >** 80% |
| 97 | Keay, 1994 | If a terminally ill patient is reported to be in pain, this is addressed by the physician and active attempts are made to reduce pain.<br>Process | **Numerator: -**<br>**Denominator: -**<br>**Exclusion:** Minor pain symptoms in cognitively intact patients<br>**Performance standard:** 100% |
| 98 | Nelson, 2006<br>Mularski, 2006 | Regular pain assessment: percentage of 4 hour intervals with documentation of pain assessment.<br>Process | **Numerator:** Number of 4 hour intervals for which pain was assessed and documented using an appropriate rating scale<br>**Denominator:** Total number of 4 hour intervals on days 0 and 1 (for patients admitted to ICU within the last 24 hours)<br>**Exclusion:** Time spend off the unit and no longer in the care of the ICU nurse (e.g. in the operating room); potential exclusions: comatose patients patients (e.g. Glasgow Coma Score of 2 or 3)<br>**Performance standard: -** |
| 99 | Nelson, 2006<br>Mularski, 2006 | Optimal pain management: percentage of 4 hour intervals with documented pain score < 3 on 1-10 scale.<br>Outcome | **Numerator:** Number of 4 hour intervals for which pain score was < 3 on 1-10 scale (or equivalent)<br>**Denominator:** Total number of 4 hour intervals on days 0 and 1 (for patients admitted to ICU within the last 24 hours)<br>**Exclusion:** Time spend off the unit and no longer in the care of the ICU nurse (e.g. in the operating room)<br>**Performance standard: -** |
| 100 | Lorenz, 2007<br>NEW Adapted by van der Ploeg, 2008 (see indicator 101) | Management of emergent pain and obstruction<br>IF a VE who was conscious during the last 7 days of life died an expected death, THEN the medical record should contain documentation about presence or absence of pain during the last 7 days of life, BECAUSE pain is common at the end of life and can be effectively treated.<br>Process | **Numerator: -**<br>**Denominator:-**<br>**Exclusion: -**<br>**Performance standard: -** |

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| 101 | $^{\text{NEW}}$ van der Ploeg, 2008<br>(Based on Lorenz, 2007, see indicator 100) | IF a vulnerable elder who was conscious during the last 7 days of life died an expected death, THEN the general practitioners record should document a pain policy (including interventions).<br>Outcome | **Numerator: -**<br>**Denominator: -**<br>**Exclusion: -**<br>**Performance standard: -** |
| 102 | Peruselli, 1997 | Palliative care services must meet the physical, psychological, social and spiritual needs of patients.<br>Outcome | **Numerator:** Number of patients with score for pain control (STAS item) dropped after 8 days of care (if initial score >0)<br>**Denominator:** Total patients x 100<br>**Exclusion: -**<br>**Performance standard:** 75% |
| 103 | Peruselli, 1997 | Palliative care services must meet the physical, psychological, social and spiritual needs of patients.<br>Outcome | **Numerator:** Number of patients with score for pain control (STAS item) of 0-1 during final week of life<br>**Denominator:** Total patients x 100<br>**Exclusion: -**<br>**Performance standard: 75%** |
| 104 | Peruselli, 1997 | Palliative care services must meet the physical, psychological, social and spiritual needs of patients.<br>Outcome | **Numerator:** Number of patients with global scores for pain (TIQ scale) dropped after 8 days of care (if initial score on the same scale > 25)<br>**Denominator:** Total patients x 100<br>**Exclusion: -**<br>**Performance standard:** 75% |
| 105 | Peruselli, 1997 | Palliative care services must meet the physical, psychological, social and spiritual needs of patients.<br>Outcome | **Numerator:** Number of patients with global scores for pain (TIQ scale) not increased over initial score during final week of care (if initial score on the same scale > 25)<br>**Denominator:** Total patients x 100<br>**Exclusion: -**<br>**Performance standard:** 75% |
| 106 | National Hospice and Palliative Care Organization (NHPCO), 2006<br>Brown University, 2006 | Family evaluation of hospice care: Symptom management<br>Questions:<br>B1: While under the care of hospice, did the patient have pain or take medicine for pain?<br>B2: How much medicine did the patient receive for his/her pain?<br>Process | **Numerator:** Those who received too much or too little help concerning pain<br>**Denominator:** Those who experience pain<br>**Exclusion:** Patients who are not enrolled in a hospice program or have disenrolled from a hospice program. Live discharged are excluded<br>**Performance standard: -** |
| 107 | National Hospice and Palliative Care Organization (NHPCO), 2006 | Comfortable dying<br>Outcome | **Numerator:** Patients whose pain was brought under control within 48 hours of admission to hospice<br>**Denominator:** Patients who were uncomfortable because of pain on admission to hospice<br>**Exclusion: -**<br>**Performance standard: -** |

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| 108 | Twaddle, 2007 | Pain assessment<br>Percentage of all patients with documentation of pain assessment within 48 hours of admission.<br>Process | **Numerator: -**<br>**Denominator: -**<br>**Exclusion: -**<br>**Performance standard: 90%** |
| 109 | Twaddle, 2007 | Use of a quantitative pain rating scale<br>Percentage of patients with pain evaluated according to a numeric or other validated pain scale.<br>Process | **Numerator: -**<br>**Denominator:** Patients reporting pain within 48 hours of admission<br>**Exclusion: -**<br>**Performance standard:** 90% |
| 110 | Twaddle, 2007 | Reduction or relief of pain<br>Percentage of patients with pain relieved or reduced (i.e. pain score of 3 or less) within 48 hours of admission.<br>Outcome | **Numerator: -**<br>**Denominator:** Patients reporting pain<br>**Exclusion: -**<br>**Performance standard: 90%** |
| 111 | Lorenz, 2007 | Management of emergent pain and obstruction<br>IF a VE with end-stage metastatic cancer is treated with opiates for pain, THEN the medical record should document a plan for management of worsening or emergent pain, BECAUSE increasing symptom burden is common with the progression of cancer and significantly impairs patient quality of life.<br>Process | **Numerator: -**<br>**Denominator: -**<br>**Exclusion: -**<br>**Performance standard: -** |
| 112 | Lorenz, 2007 | Management of emergent pain and obstruction<br>IF a VE with end-stage metastatic cancer has obstructive gastrointestinal symptoms, THEN the medical record should document a plan for management of worsening or emergent nausea and vomiting, BECAUSE increasing symptom burden is common with these conditions and significantly impairs patient quality of life.<br>Process | **Numerator: -**<br>**Denominator: -**<br>**Exclusion: -**<br>**Performance standard: -** |

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| 113 | Mularski, 2006 | Documentation of respiratory distress assessment (for non-ventilated patient) or patient-ventilator dyssynchrony (for ventilated patients) every 8 hours.<br>Process | **Numerator:** Total number of 8-hour periods during the proportion of the 24-hour day that a patient is in the ICU or under care of the ICU nurse for which dyspnea/<br>dyssynchrony is assessed and recorded using a quantitative rating scale<br>**Denominator:** Total number of 8-hour periods that a patient is in the ICU during the proportion of the 24-hour day that a patient is in the ICU or under care of the ICU nurse<br>**Exclusion:** Time Spend off the unit and no longer in the care of the ICU nurse (e.g. in the operating room)<br>**Performance standard: -** |
| 114 | Mularski, 2006 | Treatment of or management plan for respiratory distress (for non-ventilated patients) or patient-ventilator dyssynchrony (for ventilated patients) that is assessed as >3 on a 1-10 scale or greater than mild on other scales with reassessment after treatment.<br>Process/Outcome | **Numerator:** Total number of 8-hour periods during the proportion of the 24-hour day that a patient is in the ICU or under care of the ICU nurse for which respiratory distress/dyssynchony is assessed as >3 (or greater than mild) and there is a documented treatment/management plan provided and documented reassessment within 2 hours after treatment/management plan<br>**Denominator:** Total number of 8-hour periods during the proportion of the 24-hour day that a patient is in the ICU or under care of the ICU nurse for which respiratory distress/dyssynchony is assessed as >3 (or greater than mild)<br>**Exclusion:** Time spend off the unit and no longer in the care of the ICU nurse (e.g. in the operating room)<br>**Performance standard: -** |
| 115 | $^{NEW}$ Grunfeld, 2008 | Radiotherapy for uncontrolled bone pain for bony metastases<br>Providing patients with radiotherapy for bony metastases improves pain management and improves quality of life. A high proportion may indicate good quality care. (Palliative is defined as having an intent code listed as palliative or a dose level less than or equal to 3000 cGy)<br>Process | **Numerator:** Number of cases who received palliative radiation to the bones<br>**Denominator:** The entire cohort<br>**Exclusion: -**<br>**Performance standard: -** |
| 116 | $^{NEW}$ Miyashita, 2008<br>Sato, 2008 | Symptom control: Presence or absence of pain<br>Outcome | **Numerator:** Number of patients for whom this indicator was documented on admission or within the last 2 weeks of the hospitalization<br>**Denominator:** All patients who died (retrospectively identified)<br>**Exclusion: -**<br>**Performance standard: -** |

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| 117 | $^{\text{NEW}}$ Miyashita, 2008<br>Sato, 2008 | Symptom control: Degree of pain<br>Outcome | **Numerator:** Number of patients for whom this indicator was documented on admission or within the last 2 weeks of the hospitalization<br>**Denominator:** All patients who died (retrospectively identified)<br>**Exclusion: -**<br>**Performance standard: -** |
| 118 | $^{\text{NEW}}$ Miyashita, 2008<br>Sato, 2008 | Symptom control: Physician's prescription order for pain management<br>Process | **Numerator:** Number of patients for whom this indicator was documented on admission or within the last 2 weeks of the hospitalization<br>**Denominator:** All patients who died (retrospectively identified)<br>**Exclusion: -**<br>**Performance standard: -** |
| 119 | $^{\text{NEW}}$ Sato, 2008 | Symptom control: Physician's prescription order for first and second line pain management<br>Process | **Numerator:** Number of patients for whom this indicator was documented on admission or within the last 2 weeks of the hospitalization<br>**Denominator:** All patients who died (retrospectively identified)<br>**Exclusion: -**<br>**Performance standard: -** |
| 120 | $^{\text{NEW}}$ Schenck, 2010 | Physical Aspects of Care: Percent of patients screened for pain during the admission visit.<br>Process | **Numerator:** Number of patients with pain time=0<br>**Denominator:** # of patients<br>(Pain time = pain screening date – date of admission)<br>**Exclusion: -**<br>**Performance standard: -** |
| 121 | $^{\text{NEW}}$ Schenck, 2010 | Physical Aspects of Care: For patients who screened positive for pain, the percent with clinical assessment within 1 day of screening.<br>Process | **Numerator:** Number of patients with (0<=Clinical Pain Time<=1)<br>**Denominator:** Patients with pain<br>(Clinical Pain Time= screening date – pain assessment date)<br>**Exclusion: -**<br>**Performance standard: -** |
| 122 | $^{\text{NEW}}$ Schenck, 2010 | Physical Aspects of Care: For patients who screened positive for pain, the percent with any treatment within 1 day of screening.<br>Process | **Numerator:** Number of patients with (0<=Pain Treatment Time<=1) and (pain treatment="Y")<br>(Pain Treatment Time = date of treatment – pain assessment date)<br>**Denominator:** Patients with pain<br>**Exclusion: -**<br>**Performance standard: -** |
| 123 | $^{\text{NEW}}$ Schenck, 2010 | Physical Aspects of Care: For patients who screened positive for pain, the percent who have an order for regularly scheduled (not PRN) pain medication within 1 day of screening.<br>Process | **Numerator:** Number of patients with (0<=Pain Treatment Time<=1) and (Treatment=1)<br>(Pain Treatment time = date of treatment – pain assessment date<br>Treatment = 1 if type of treatment equals "Scheduled medication, opioid" or "Scheduled medication, non-opioid")<br>**Denominator:** Number of patients with pain<br>**Exclusion: -**<br>**Performance standard: -** |

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| 124 | NEW Schenck, 2010 | Physical Aspects of Care: For patients who screened positive for pain, the percent with improvement within 1 day of screening.<br>Outcome | **Numerator:** Number of patients with (0<=Improvement Time<=1) and (Improvement=1)<br>(Improvement Time = Second Pain assessment date-Pain assessment date)<br>**Denominator:** Patients with pain<br>**Exclusion: -**<br>**Performance standard: -** |
| 125 | NEW Schenck, 2010 | Physical Aspects of Care: For patients who screened positive for pain, the percent whose pain was at a comfortable level within 2 days of screening (patient report of comfort or mild pain based on standard pain rating scale).<br>Outcome | **Numerator:** Number of patients with (0<=Improvement Time<=2) and (Comfort =1)<br>(Improvement Time = Second Pain assessment date-Pain assessment date<br>Comfort =1 if patient reports comfort or mild pain based on standard pain rating scale)<br>**Denominator:** Patients with pain<br>**Exclusion: -**<br>**Performance standard: -** |
| 126 | NEW Schenck, 2010 | Physical Aspects of Care: Percent of patients with cognitive and language problems receiving pain assessment appropriate to communication needs.<br>Process | **Numerator:** (Number of patients with dementia or confusion and pain assessment = observational) + (number of patients who are deaf or non-English speaking with pain assessment = translated materials)<br>**Denominator:** Number of patients with dementia, confusion, deafness or non-English<br>**Exclusion: -**<br>**Performance standard: -** |
| 127 | NEW Schenck, 2010 | Care for the Imminently Dying: Percent of patients who had moderate to severe pain on a standard rating scale at any time in the last week of life.<br>Outcome | **Numerator:** Number of patients with Pain in last week= “Moderate” or “Severe”<br>**Denominator:** Number of patients who died<br>**Exclusion: -**<br>**Performance standard: -** |
| 128 | NEW Lorenz, 2009 | Pain: IF a cancer patient has a cancer-related outpatient visit THEN there should be screening for the presence or absence and intensity of pain using a numeric pain score.<br>Process | **Numerator**: -<br>**Denominator**: -<br>**Exclusion**: -<br>**Performance standard**: - |
| 129 | NEW Lorenz, 2009 | Pain: IF a cancer patient is admitted to a hospital THEN there should be screening for the presence or absence of pain.<br>Process | **Numerator**: -<br>**Denominator**: -<br>**Exclusion**: -<br>**Performance standard**: - |

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| 130 | NEW Lorenz, 2009 | Pain: IF a patient with cancer pain is started on a long-acting opioid formulation, THEN a short-acting opioid formulation for breakthrough pain should also be provided.<br><br>Process | **Numerator**: -<br>**Denominator**: -<br>**Exclusion**: -<br>**Performance standard**: - |
| 131 | NEW Lorenz, 2009 | Pain: IF a patient's outpatient cancer pain regimen is changed, THEN there should be an assessment of the effectiveness of treatment at or before the next outpatient visit with that provider or at another cancer-related outpatient visit.<br><br>Process | **Numerator**: -<br>**Denominator**: -<br>**Exclusion**: -<br>**Performance standard**: - |
| 132 | NEW Lorenz, 2009 | Pain: IF a patient has advanced cancer and receives radiation treatment for painful bone metastases THEN s/he should be offered single-fraction radiation OR there should be documentation of a contraindication to single-fraction treatment.<br><br>Process | **Numerator**: -<br>**Denominator**: -<br>**Exclusion**: -<br>**Performance standard**: - |
| 133 | NEW Lorenz, 2009 | Pain: IF a cancer patient is treated for spinal cord compression THEN there should be follow-up of neurologic symptoms and signs within 1 week after treatment is completed.<br><br>Process | **Numerator**: -<br>**Denominator**: -<br>**Exclusion**: -<br>**Performance standard**: - |
| 134 | NEW Claessen, 2011 | Management of pain and other physical symptoms: Percentage of patients with moderate to severe pain<br><br>Pain is a common symptom in the palliative phase. The quality of both pharmacological and non-pharmacological interventions influences the severity of pain.<br><br>Outcome | **Numerator:** The number of patients with a pain score of 4 or above on the NRS (average over 3 days)<br>**Denominator:** The total number of patients for whom this indicator is measured<br>**Exclusion:** Comatose and deeply sedated patients<br>**Performance standard: -** |

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| 135 | NEW Eagar, 2010 | Change in pain<br>Change in pain is calculated by the difference in pain score from the beginning of a phase to the end of phase and is calculated using both PSS pain and SAS pain measures.<br>Outcome | Percentage of patients with absent or mild pain at the beginning of their phase of palliative care have absent or mild pain at the end of the phase<br>**Numerator**: -<br>**Denominator**: -<br>**Exclusion**: -<br>**Performance standard:** 90%<br>Percentage of patients with moderate or severe pain at the beginning of their phase of palliative care have absent or mild pain at the end of the phase<br>**Numerator**: -<br>**Denominator**: -<br>**Exclusion**: -<br>**Performance standard**: 60% |
| 136 | Mularski, 2006 | Documentation of opioids, benzodiazepines, or similar agents prescribed to manage distress or dyspnea for non-comatose patients undergoing terminal withdrawal of mechanical ventilation.<br>Process | **Numerator:** Total number of non-comatose patients for whom mechanical ventilation is withdrawn in anticipation of death who have an order writer for opiates or benzodiazepines as scheduled or as needed<br>**Denominator:** Total number of non-comatose patients for whom mechanical ventilation is withdrawn in anticipation of death<br>**Exclusion:** Comatose patients (e.g. Glasgow Coma Score of 2 or 3)<br>**Performance standard: -** |
| 137 | Keay, 1994 | Dyspnea, if present, is addressed and attempts are made to minimize dyspnea.<br>Process | **Numerator: -**<br>**Denominator: -**<br>**Exclusion:** Physicians not made aware of dyspnea<br>**Performance standard:** 100% |
| 138 | Peruselli, 1997 | Palliative care services must meet the physical, psychological, social and spiritual needs of patients.<br>Outcome | **Numerator:** Number of patients with global scores for breathing difficulties (TIQ scale) dropped after 8 days of care (if initial score on the same scale > 25)<br>**Denominator:** Total patients x 100<br>**Exclusion: -**<br>**Performance standard:** 75% |
| 139 | Peruselli, 1997 | Palliative care services must meet the physical, psychological, social and spiritual needs of patients.<br>Outcome | **Numerator:** Number of patients with global scores for breathing difficulties (TIQ scale) not increased over initial score during final week of care (if initial score on the same scale > 25)<br>**Denominator:** Total patients x 100<br>**Exclusion: -**<br>**Performance standard:** 75% |

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| 140 | National Hospice and Palliative Care Organization (NHPCO), 2006<br>Brown University, 2006 | Family evaluation of hospice care: Symptom management<br><br>Questions:<br>B5: While under the care of hospice, did the patient have trouble breathing?<br>B6: How much help in dealing with his/her breathing did the patient receive while under the care of hospice?<br><br>Outcome | **Numerator:** Those who received too much or too little help concerning shortness of breath<br>**Denominator:** Those who experience shortness of breath<br>**Exclusion:** Patients who are not enrolled in a hospice program or have disenrolled from a hospice program. Live discharged are excluded<br>**Exclusion: -**<br>**Performance standard: -** |
| 141 | Twaddle, 2007 | Dyspnea assessment<br><br>Percentage of all patients with documentation of dyspnea assessment within 48 hours of admission.<br><br>Process | **Numerator: -**<br>**Denominator: -**<br>**Exclusion: -**<br>**Performance standard:** 90% |
| 142 | Twaddle, 2007 | Reduction or relief of dyspnea<br><br>Percentage of patients with dyspnea relieved or reduced (i.e. score of 3 or less on a 10-point scale) within 48 hours of admission.<br><br>Outcome | **Numerator: -**<br>**Denominator:** Patients reporting dyspnea<br>**Exclusion: -**<br>**Performance standard:** 90% |
| 143 | Lorenz, 2007 | Mechanical ventilator withdrawal<br><br>IF a non-comatose VE is not expected to survive, and a mechanical ventilator is withdrawn or withheld, THEN the chart should document whether the patient has dyspnea, and the patient should receive (or have orders available for) an opiate, benzodiazepine, or barbiturate infusion, BECAUSE dyspnea can be controlled in the setting of comfort care when mechanical ventilation is withdrawn or withheld.<br><br>Process | **Numerator: -**<br>**Denominator: -**<br>**Exclusion: -**<br>**Performance standard: -** |

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| 144 | Lorenz, 2007<br>NEW Adapted by van der Ploeg, 2008<br>(see indicator 145) | Management of emergent dyspnea<br>IF a VE who has dyspnea in the last 7 days of life died an expected death, THEN the chart should document dyspnea care and follow-up, BECAUSE dyspnea can be effectively treated with oxygen and pharmacological agents.<br>Process | **Numerator: -**<br>**Denominator: -**<br>**Exclusion: -**<br>**Performance standard: -** |
| 145 | NEW van der Ploeg, 2008<br>(Based on Lorenz, 2007, see indicator 144) | IF a vulnerable elder who had dyspnea in the last 7 days of life died an expected death, THEN the general practitioners record should document a dyspnea policy (including interventions).<br>Outcome | **Numerator: -**<br>**Denominator: -**<br>**Exclusion: -**<br>**Performance standard: -** |
| 146 | Lorenz, 2007 | Dyspnea assessment<br>IF a VE is diagnosed with lung cancer, or cancer metastatic to lung, NYHA Class III to IV CHF, or oxygen-dependent pulmonary disease, THEN a self-reported assessment of dyspnea should be documented in the outpatient chart, BECAUSE dyspnea is common in these conditions, and there are effective treatments for addressing dyspnea.<br>Process | **Numerator: -**<br>**Denominator: -**<br>**Exclusion: -**<br>**Performance standard: -** |
| 147 | Lorenz, 2007<br>NEW van der Ploeg, 2008 | Treatment of dyspnea<br>IF a VE with metastatic cancer or oxygen-dependent pulmonary disease has dyspnea refractory to non-opiate medications, THEN opiate medications should be offered, BECAUSE opiates effectively treat dyspnea from advanced cancer and chronic obstructive pulmonary disease.<br>Process | **Numerator: -**<br>**Denominator: -**<br>**Exclusion: -**<br>**Performance standard: -** |

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| 148 | Lorenz, 2007 | Management of emergent dyspnea<br>IF a VE is in hospice or has a preference for no hospitalization and is living with oxygen-dependent pulmonary disease, lung cancer, or NYHA Class III to IV CHF, THEN the medical record should document a plan for management of worsening or emergent dyspnea, BECAUSE increasing symptom burden is common with the progression of these illnesses and significantly impairs patient quality of life.<br>Process | **Numerator: -**<br>**Denominator: -**<br>**Exclusion: -**<br>**Performance standard: -** |
| 149 | $^{\text{NEW}}$ Miyashita, 2008<br>Sato, 2008 | Symptom control: Presence or absence of dyspnea<br>Outcome | **Numerator:** Number of patients for whom this indicator was documented on admission or within the last 2 weeks of the hospitalization<br>**Denominator:** All patients who died (retrospectively identified)<br>**Exclusion: -**<br>**Performance standard: -** |
| 150 | $^{\text{NEW}}$ Miyashita, 2008<br>Sato, 2008 | Symptom control: Physician’s prescription order for dyspnea<br>Process | **Numerator:** Number of patients for whom this indicator was documented on admission or within the last 2 weeks of the hospitalization<br>**Denominator:** All patients who died (retrospectively identified)<br>**Exclusion: -**<br>**Performance standard: -** |
| 151 | $^{\text{NEW}}$ Schenck, 2010 | Physical Aspects of Care: Percent of patients who were screened for shortness of breath during the admission visit.<br>Process | **Numerator:** Number of patients with dyspnea time=0<br>(Dyspnea time = dyspnea screening date –date of admission)<br>**Denominator:** # of patients<br>**Exclusion: -**<br>**Performance standard: -** |
| 152 | $^{\text{NEW}}$ Schenck, 2010 | Physical Aspects of Care: For patients who screened positive for dyspnea, the percent who received treatment within 1 day of screening.<br>Process | **Numerator:** Number of patients with (0<=Dyspnea Treatment Time<=1 and dyspnea treatment=”Y”)<br>Dyspnea Treatment time = date of treatment – dyspnea assessment date<br>**Denominator:** # patients with dyspnea<br>**Exclusion: -**<br>**Performance standard: -** |
| 153 | $^{\text{NEW}}$ Schenck, 2010 | Physical Aspects of Care: For patients who screened positive for dyspnea, the percent of patients who improved within 1 day of screening.<br>Outcome | **Numerator:** Number of patients with (0<=Improvement Time<=1 and Improvement=1)<br>(Improvement Time = Second Dyspnea assessment date-Dyspnea assessment date)<br>**Denominator:** # patients with dyspnea<br>**Exclusion: -**<br>**Performance standard: -** |

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| 154 | $^{NEW}$ Schenck, 2010 | Physical Aspects of Care: For patients with moderate or severe shortness of breath, the percent with treatment or satisfied within 4 hours.<br>Process/Outcome | **Numerator:** Number of patients with moderate or severe shortness of breath with treatment or satisfied within 4 hours ="Y"<br>**Denominator:** Total number patients with moderate or severe dyspnea<br>**Exclusion: -**<br>**Performance standard: -** |
| 155 | $^{NEW}$ Lorenz, 2009 | Dyspnea IF a patient with cancer reports new or worsening dyspnea, THEN there should be documentation of cause or of investigation of at least 1 of the following: hypoxia, anemia, bronchospasm or chronic obstructive pulmonary disease, pleural effusion, tumor obstruction of bronchi or the trachea, pneumonia, or pulmonary embolism.<br>Process | **Numerator**: -<br>**Denominator**: -<br>**Exclusion**: -<br>**Performance standard**: - |
| 156 | $^{NEW}$ Lorenz, 2009 | Dyspnea IF an outpatient with primary lung cancer or advanced cancer reports new or worsening dyspnea, THEN s/he should be offered symptomatic management or treatment directed at an underlying cause within 1 month.<br>Process | **Numerator**: -<br>**Denominator**: -<br>**Exclusion**: -<br>**Performance standard**: - |
| 157 | $^{NEW}$ Lorenz, 2009 | Dyspnea IF an inpatient with primary lung cancer or advanced cancer has dyspnea on admission, THEN s/he should be offered symptomatic management or treatment directed at an underlying cause within 24 hours.<br>Process | **Numerator**: -<br>**Denominator**: -<br>**Exclusion**: -<br>**Performance standard**: - |
| 158 | $^{NEW}$ Lorenz, 2009 | Dyspnea IF a patient with cancer in the hospital is treated for dyspnea, THEN there should be an assessment within 24 hours that the treatment was effective in relieving dyspnea OR that a change in treatment for dyspnea was made.<br>Process | **Numerator**: -<br>**Denominator**: -<br>**Exclusion**: -<br>**Performance standard**: - |

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| 159 | NEW Lorenz, 2009 | Dyspnea IF a cancer patient has dyspnea and a malignant pleural effusion, THEN s/he should be offered thoracentesis within 1 month of the initial diagnosis of the effusion OR other treatment (e.g., diuresis) should result in a reduction in the effusion or symptomatic dyspnea.<br>Process | **Numerator**: -<br>**Denominator**: -<br>**Exclusion**: -<br>**Performance standard**: - |
| 160 | NEW Lorenz, 2009 | Dyspnea IF a cancer patient with a malignant pleural effusion undergoes thoracentesis, THEN there should be a repeat assessment of dyspnea within 1 week.<br>Process | **Numerator**: -<br>**Denominator**: -<br>**Exclusion**: -<br>**Performance standard**: - |
| 161 | NEW Claessen, 2011 | Management of pain and other physical symptoms: Percentage of patients with shortness of breath<br>Shortness of breath often occurs in the palliative phase and can to a certain extent be influenced by pharmacological interventions (e.g. antibiotics, anticoagulants) and non-pharmacological interventions (e.g. oxygen administration, suction).<br>Outcome | **Numerator:** The number of patients with a shortness of breath score of 4 or above on the NRS (average over 3 days)<br>**Denominator:** The total number of patients for whom this indicator is measured<br>**Exclusion:** Comatose and deeply sedated patients<br>**Performance standard: -** |
| 162 | Peruselli, 1997 | Palliative care services must meet the physical, psychological, social and spiritual needs of patients.<br>Outcome | **Numerator:** Number of patients with global scores for constipation (TIQ scale) dropped after 8 days of care (if initial score on the same scale > 25)<br>**Denominator:** Total patients x 100<br>**Exclusion: -**<br>**Performance standard:** 75% |
| 163 | Peruselli, 1997 | Palliative care services must meet the physical, psychological, social and spiritual needs of patients.<br>Outcome | **Numerator:** Number of patients with global scores for constipation (TIQ scale) not increased over initial score during final week of care (if initial score on the same scale > 25)<br>**Denominator:** Total patients x 100<br>**Exclusion: -**<br>**Performance standard:** 75% |
| 164 | Peruselli, 1997 | Palliative care services must meet the physical, psychological, social and spiritual needs of patients.<br>Outcome | **Numerator:** Number of patients with global scores for gastrointestinal symptoms (TIQ scale) dropped after 8 days of care (if initial score on the same scale > 25)<br>**Denominator:** Total patients x 100<br>**Performance standard:** 75% |

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| 165 | Peruselli, 1997 | Palliative care services must meet the physical, psychological, social and spiritual needs of patients.<br>Outcome | **Numerator:** Number of patients with global scores for gastrointestinal symptoms (TIQ scale) not increased over initial score during final week of care (if initial score on the same scale > 25)<br>**Denominator:** Total patients x 100<br>**Exclusion: -**<br>**Performance standard:** 75% |
| 166 | Twaddle, 2007 | Bowel regimen ordered in conjunction with opioid administration<br>Percentage of patients receiving opioids who had an order for a bowel regimen written within 24 hours of order for the opioid.<br>Process | **Numerator: -**<br>**Denominator: -**<br>**Exclusion: -**<br>**Performance standard:** 90% |
| 167 | NEW Grunfeld, 2008 | Potent antiemetics for emetogenic chemotherapy<br>Potent anti-emetic therapy for highly emetogenic chemotherapy treatments greatly controls nausea and vomiting. A high proportion may indicate good quality care.<br>Process | **Numerator:** Number of cases 65 years of age and older who had a prescription for a potent antiemetic<br>**Denominator:** All cases 65 years of age and older<br>**Exclusion: -**<br>**Performance standard:-** |
| 168 | NEW Schenck, 2010 | Physical Aspects of Care: For patients who screened positive for nausea, the percent who received treatment within 1 day of screening.<br>Process | **Numerator:** Number of patients with (0<=Nausea Treatment Time<=1 and nausea treatment=”Y”)<br>(Nausea Treatment time = date of treatment – nausea assessment date)<br>**Denominator:** Number of patients with nausea<br>**Exclusion: -**<br>**Performance standard: -** |
| 169 | NEW Schenck, 2010 | Physical Aspects of Care: Percent of patients with bowel function assessed at least weekly.<br>Process | **Numerator:** Number of patients with bowel function assessed weekly = “Y”<br>**Denominator:** Total # patients<br>**Exclusion: -**<br>**Performance standard: -** |
| 170 | NEW Schenck, 2010 | Physical Aspects of Care: For patients who screened positive for constipation, the percent who receive treatment within 1 day of screening.<br>Process | **Numerator:** Number of patients with (0<=Constipation Time<=1 and constipation treatment=”Y”)<br>**Denominator:** # patients with constipation (Constipation treatment time= date of treatment - constipation assessment date)<br>**Exclusion: -**<br>**Performance standard: -** |
| 171 | NEW Schenck, 2010 | Physical Aspects of Care: Percent of residents on opioids for whom a bowel regimen is established.<br>Process | **Numerator:** Number of patients with opioids=”Y” and bowel regimen=”Y”<br>**Denominator:** # patients on opioids<br>**Exclusion: -**<br>**Performance standard: -** |

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| 172 | $^{\text{NEW}}$ Schenck, 2010 | Physical Aspects of Care: Percent of residents on opioids who have a bowel regimen within 1 day of opioid initiation.<br>Process | **Numerator:** Number of patients with (0≤Time≤1 and opioids=”Y” and bowel regimen=”Y” )<br>**Denominator:** # patients on opioids (Time = bowel regimen date – pain treatment date)<br>**Performance standard: -** |
| 173 | $^{\text{NEW}}$ Lorenz, 2009 | Pain: IF a patient with cancer pain is started on chronic opioid treatment THEN s/he should be offered either a prescription or non-prescription bowel regimen within 24 hours OR there should be documented contraindication to a bowel regimen.<br>Process | **Numerator**: -<br>**Denominator**: -<br>**Exclusion**: -<br>**Performance standard**: - |
| 174 | $^{\text{NEW}}$ Lorenz, 2009 | Nausea and vomiting IF a patient with cancer undergoing moderately or highly emetic chemotherapy or with advanced cancer affecting the gastrointestinal tract or abdomen is seen for a visit in a cancer-related outpatient setting, THEN the presence or absence of nausea or vomiting should be assessed at every visit.<br>Process | **Numerator**: -<br>**Denominator**: -<br>**Exclusion**: -<br>**Performance standard**: - |
| 175 | $^{\text{NEW}}$ Lorenz, 2009 | Nausea and vomiting IF a patient with advanced cancer affecting the gastrointestinal tract or abdomen is admitted to a hospital, THEN the presence or absence of nausea or vomiting should be assessed within 24 hours.<br>Process | **Numerator**: -<br>**Denominator**: -<br>**Exclusion**: -<br>**Performance standard**: - |
| 176 | $^{\text{NEW}}$ Lorenz, 2009 | Nausea and vomiting IF a patient with cancer is undergoing chemotherapy treatment with a high acute emetic risk, THEN a 3-drug regimen including single doses of a 5-HT3 receptor antagonist, dexamethasone, and selective neurokinin-1 receptor blocker should be given immediately before chemotherapy.<br>Process | **Numerator**: -<br>**Denominator**: -<br>**Exclusion**: -<br>**Performance standard**: - |

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| 177 | $^{\text{NEW}}$ Lorenz, 2009 | Nausea and vomiting IF a patient with cancer is undergoing chemotherapy treatment with a moderate acute emetic risk, THEN a 2-drug regimen including a 5-HT3 receptor antagonist and dexamethasone should be given immediately before chemotherapy.<br>Process | **Numerator**: -<br>**Denominator**: -<br>**Exclusion**: -<br>**Performance standard**: - |
| 178 | $^{\text{NEW}}$ Lorenz, 2009 | Nausea and vomiting IF a patient with cancer reports nausea or vomiting on admission to the hospital, THEN within 24 hours potential underlying causes should be assessed.<br>Process | **Numerator**: -<br>**Denominator**: -<br>**Exclusion**: -<br>**Performance standard**: - |
| 179 | $^{\text{NEW}}$ Lorenz, 2009 | Nausea and vomiting IF an inpatient with cancer has nausea or vomiting, THEN within 24 hours of the initial report of nausea and vomiting, the patient should be offered a change in therapy.<br>Process | **Numerator**: -<br>**Denominator**: -<br>**Exclusion**: -<br>**Performance standard**: - |
| 180 | $^{\text{NEW}}$ Lorenz, 2009 | Nausea and vomiting IF an outpatient with cancer not receiving chemotherapy or radiation is treated for nausea or vomiting with an antiemetic medication, THEN the effectiveness of treatment should be evaluated before or on the next visit to the same outpatient site.<br>Process | **Numerator**: -<br>**Denominator**: -<br>**Exclusion**: -<br>**Performance standard**: - |
| 181 | $^{\text{NEW}}$ Lorenz, 2009 | Anorexia/weight loss IF a patient presents for an initial visit for cancer affecting the oropharynx or gastrointestinal tract or advanced cancer at a cancer-related outpatient site, THEN there should be an assessment for the presence or absence of anorexia or dysphagia.<br>Process | **Numerator**: -<br>**Denominator**: -<br>**Exclusion**: -<br>**Performance standard**: - |

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| 182 | $^{\text{NEW}}$ Lorenz, 2009 | Anorexia/weight loss IF a cancer patient is treated with an appetite stimulant for anorexia, THEN there should be an assessment before or on the next visit to the same outpatient site of whether there was an improvement in anorexia.<br>Process | **Numerator**: -<br>**Denominator**: -<br>**Exclusion**: -<br>**Performance standard**: - |
| 183 | $^{\text{NEW}}$ Lorenz, 2009 | Anorexia/weight loss IF a cancer patient is treated with enteral or parenteral nutrition, THEN there should be an assessment before starting nutrition that there was difficulty maintaining nutrition due to significant gastrointestinal issues and that life expectancy was at least 1 month.<br>Process | **Numerator**: -<br>**Denominator**: -<br>**Exclusion**: -<br>**Performance standard**: - |
| 184 | $^{\text{NEW}}$ Claessen, 2011 | Management of pain and other physical symptoms: Percentage of patients with constipation<br>Constipation is a frequent and burdensome problem in the palliative phase and can be influenced particularly by pharmacological interventions (e.g. laxantia).<br>Outcome | **Numerator:** The number of patients with a constipation score of 4 or above on the NRS (average over 3 days)<br>**Denominator:** The total number of patients for whom this indicator is measured<br>**Exclusion:** Comatose and deeply sedated patients<br>**Performance standard: -** |
| 185 | Peruselli, 1997 | Palliative care services must meet the physical, psychological, social and spiritual needs of patients.<br>Outcome | **Numerator:** Number of patients with global scores for fatigue (TIQ scale) dropped after 8 days of care (if initial score on the same scale > 25)<br>**Denominator:** Total patients x 100<br>**Exclusion: -**<br>**Performance standard:** 75% |
| 186 | Peruselli, 1997 | Palliative care services must meet the physical, psychological, social and spiritual needs of patients.<br>Outcome | **Numerator:** Number of patients with global scores for fatigue (TIQ scale) not increased over initial score during final week of care (if initial score on the same scale > 25)<br>**Denominator:** Total patients x 100<br>**Exclusion: -**<br>**Performance standard:** 75% |

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| 187 | NEW Lorenz, 2009 | Fatigue/anemia IF a cancer patient is seen for an initial visit or any visit while undergoing chemotherapy at a cancer-related outpatient site, THEN there should be an assessment of the presence or absence of fatigue.<br>Process | **Numerator**: -<br>**Denominator**: -<br>**Exclusion**: -<br>**Performance standard**: - |
| 188 | NEW Lorenz, 2009 | Fatigue/anemia<br>IF a known cancer patient is newly diagnosed with advanced cancer, THEN there should be an assessment of the presence or absence of fatigue.<br>Process | **Numerator**: -<br>**Denominator**: -<br>**Exclusion**: -<br>**Performance standard**: - |
| 189 | NEW Lorenz, 2009 | Fatigue/anemia IF a patient with cancer is found to have anemia with a hemoglobin <10 g/dL, THEN the presence and severity of anemia- related symptoms (e.g., fatigue, dyspnea, and lightheadedness) should be evaluated.<br>Process | **Numerator**: -<br>**Denominator**: -<br>**Exclusion**: -<br>**Performance standard**: - |
| 190 | NEW Lorenz, 2009 | Fatigue/anemia IF a patient with cancer is found to have severe, symptomatic anemia (hemoglobin <8 g/dL), THEN transfusion with packed red cells should be offered to the patient within 24 hours.<br>Process | **Numerator**: -<br>**Denominator**: -<br>**Exclusion**: -<br>**Performance standard**: - |
| 191 | NEW Claessen, 2011 | Management of pain and other physical symptoms: Percentage of patients with fatigue<br>Fatigue is one of the most common symptoms in cancer patients. Both pharmacological and non-pharmacological interventions (e.g. relaxation therapy) are appropriate treatment options.<br>Outcome | **Numerator:** The number of patients with a fatigue score of 4 or above on the NRS (average over 3 days)<br>**Denominator:** The total number of patients for whom this indicator is measured<br>**Exclusion:** Comatose and deeply sedated patients<br>**Performance standard: -** |

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| 192 | Yabroff, 2004 | Percentage of patients within and among health facilities or systems with evidence that symptom relief was achieved and unmet needs were met with appropriate response or resolved.<br>Outcome | **Numerator: -**<br>**Denominator: -**<br>**Exclusion: -**<br>**Performance standard: -** |
| 193 | Peruselli, 1997 | Palliative care services must meet the physical, psychological, social and spiritual needs of patients.<br>Outcome | **Numerator:** Number of patients with score for symptom control other than pain (STAS item) dropped after 8 days of care (if initial score >0)<br>**Denominator:** Total patients x 100<br>**Exclusion: -**<br>**Performance standard:** 75% |
| 194 | Peruselli, 1997 | Palliative care services must meet the physical, psychological, social and spiritual needs of patients.<br>Outcome | **Numerator:** Number of patients with score symptom control other than pain (STAS item) of 0-1 during final week of life<br>**Denominator:** Total patients x 100<br>**Exclusion: -**<br>**Performance standard:** 75% |
| 195 | Peruselli, 1997 | Palliative care services must meet the physical, psychological, social and spiritual needs of patients.<br>Outcome | **Numerator:** Number of patients with global scores for physical symptoms (= comprising TIQ scales: fatigue, gastrointestinal symptoms and global health status) dropped after 8 days of care (if initial score on the same scale > 25)<br>**Denominator:** Total patients x 100<br>**Exclusion: -**<br>**Performance standard:** 75% |
| 196 | Peruselli, 1997 | Palliative care services must meet the physical, psychological, social and spiritual needs of patients.<br>Outcome | **Numerator:** Number of patients with global scores for physical symptoms (= comprising TIQ scales: fatigue, gastrointestinal symptoms and global health status) not increased over initial score during final week of care (if initial score on the same scale > 25)<br>**Denominator:** Total patients x 100<br>**Exclusion: -**<br>**Performance standard:** 75% |
| 197 | Peruselli, 1997 | Palliative care services must meet the physical, psychological, social and spiritual needs of patients.<br>Outcome | **Numerator:** Number of patients with global scores for global health status (TIQ scale) dropped after 8 days of care (if initial score on the same scale > 25)<br>**Denominator:** Total patients x 100<br>**Exclusion: -**<br>**Performance standard:** 75% |
| 198 | Peruselli, 1997 | Palliative care services must meet the physical, psychological, social and spiritual needs of patients.<br>Outcome | **Numerator:** Number of patients with global scores for global health status (TIQ scale) not increased over initial score during final week of care (if initial score on the same scale > 25)<br>**Denominator:** Total patients x 100<br>**Exclusion: -**<br>**Performance standard:** 75% |

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| 199 | NEW Sato, 2008 | Symptom control: Effect of rescue medication for any physical distress<br>Outcome | **Numerator:** Number of patients for whom this indicator was documented on admission or within the last 2 weeks of the hospitalization<br>**Denominator:** All patients who died (retrospectively identified)<br>**Exclusion: -**<br>**Performance standard: -** |
| **200** | NEW van der Ploeg, 2008<br>This indicator suits domain 2,3,4 and 8. | IF a vulnerable elder dies with a progressive incurable disease (for example metastatic cancer, or dementia) THEN there should be evidence within 6 months prior to death that they received a comprehensive assessment including:<br>• Pain;<br>• Anxiety, depression;<br>• Vomiting and dyspnea;<br>• Spiritual and existential concerns;<br>• Caregiver burdens/need for practical assistance;<br>• Wishes concerning medical treatment and care at the end of life;<br>A discussion about and if possible the determination of a surrogate decision maker.<br>Process | **Numerator: -**<br>**Denominator: -**<br>**Exclusion: -**<br>**Performance standard: -** |
| 201 | NEW Miyashita, 2008<br>Sato, 2008 | Symptom control: Observation and care of mouth<br>Process | **Numerator:** Number of patients for whom this indicator was documented on admission or within the last 2 weeks of the hospitalization<br>**Denominator:** All patients who died (retrospectively identified)<br>**Exclusion: -**<br>**Performance standard: -** |
| 202 | NEW Lorenz, 2009 | Pain: IF a cancer patient has new neurologic symptoms or findings on physical examination consistent with spinal cord compression THEN s/he should be treated with steroids as soon as possible, but within 24 hours OR a contraindication to steroids should be documented.<br>Process | **Numerator**: -<br>**Denominator**: -<br>**Exclusion**: -<br>**Performance standard**: - |

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| 203 | $^{NEW}$ Lorenz, 2009 | Pain: IF a cancer patient has new neurologic symptoms or findings on physical examination consistent with spinal cord compression THEN a whole-spine MRI scan or myelography should be performed as soon as possible, but within 24 hours OR there should be documentation of why an MRI scan was not appropriate.<br>Process | **Numerator**: -<br>**Denominator**: -<br>**Exclusion**: -<br>**Performance standard**: - |
| 204 | $^{NEW}$ Lorenz, 2009 | Pain: IF a cancer patient has confirmation of spinal cord compression on radiologic examination, THEN radiotherapy or surgical decompression should be initiated within 24 hours OR a contraindication for such therapy should be documented.<br>Process | **Numerator**: -<br>**Denominator**: -<br>**Exclusion**: -<br>**Performance standard**: - |
| 205 | $^{NEW}$ Lorenz, 2009 | Treatment-associated toxicities - Diarrhea IF a patient with cancer is undergoing chemotherapy and has diarrhea THEN to classify the diarrhea as complicated or uncomplicated all of the following should be assessed: history of onset and duration; number of stools and stool composition; and at least 1 of the associated symptoms (fever, dizziness, abdominal pain/cramping, nausea/vomiting, decreased performance status, sepsis, fever, bleeding, or dehydration).<br>Process | **Numerator**: -<br>**Denominator**: -<br>**Exclusion**: -<br>**Performance standard**: - |

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| 206 | $^{\text{NEW}}$ Lorenz, 2009 | Treatment-associated toxicities - Diarrhea IF a patient with cancer is undergoing chemotherapy with a high risk (>10%) of chemotherapy-induced diarrhea THEN an antidiarrheal agent should be prescribed on or before treatment is initiated.<br>Process | **Numerator**: -<br>**Denominator**: -<br>**Exclusion**: -<br>**Performance standard**: - |
| 207 | $^{\text{NEW}}$ Lorenz, 2009 | Skin rash IF a patient with cancer who is being treated with agents that block epidermal growth factor receptors, THEN the presence and severity of skin rash should be evaluated within 1 month after starting the treatment and at each visit.<br>Process | **Numerator**: -<br>**Denominator**: -<br>**Exclusion**: -<br>**Performance standard**: - |
| **Domain 3: Psychological and psychiatric aspects of care (33 indicators)** | | | |
| | **Reference/ year** | **Description/type of indicator** | **Numerator/Denominator/Exclusion/ Performance standard** |
| 208 | Peruselli, 1997 | Palliative care services must meet the physical, psychological, social and spiritual needs of patients.<br>Outcome | **Numerator**: Number of patients with global scores for functional impairment (TIQ scale) dropped after 8 days of care (if initial score on the same scale > 25)<br>**Denominator**: Total patients x 100<br>**Exclusion**: -<br>**Performance standard**: 75% |
| 209 | Peruselli, 1997 | Palliative care services must meet the physical, psychological, social and spiritual needs of patients.<br>Outcome | **Numerator**: Number of patients with global scores for functional impairment (TIQ scale) not increased over initial score during final week of care (if initial score on the same scale > 25)<br>**Denominator**: Total patients x 100<br>**Exclusion**: -<br>**Performance standard**: 75% |
| 210 | Saliba, 2004 | IF a nursing home resident was conscious during any of the last 7 days of life and died an expected death THEN there should be medical record documentation about emotional distress (presence, absence, or inability to assess) in the last 7 days of life.<br>Process | **Numerator**:-<br>**Denominator**: -<br>**Exclusion**: -<br>**Performance standard**: - |
| 211 | Peruselli, 1997 | Palliative care services must meet the physical, psychological, social and spiritual needs of patients.<br>Outcome | **Numerator**: Number of patients with score for patient anxiety (STAS item) dropped after 8 days of care (if initial score >0)<br>**Denominator**: Total patients x 100<br>**Performance standard**: 75% |

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| 212 | Peruselli, 1997 | Palliative care services must meet the physical, psychological, social and spiritual needs of patients.<br>Outcome | **Numerator**: Number of patients with score for patient anxiety (STAS item) of 0-1 during final week of life<br>**Denominator**: Total patients x 100<br>**Exclusion**: -<br>**Performance standard**: 75% |
| 213 | Peruselli, 1997 | Palliative care services must meet the physical, psychological, social and spiritual needs of patients.<br>Outcome | **Numerator**: Number of patients with score for family anxiety (STAS item) dropped after 8 days of care (if initial score >0)<br>**Denominator**: Total patients x 100<br>**Exclusion**: -<br>**Performance standard**: 75% |
| 214 | Peruselli, 1997 | Palliative care services must meet the physical, psychological, social and spiritual needs of patients.<br>Outcome | **Numerator**: Number of patients with score for family anxiety (STAS item) of 0-1 during final week of life<br>**Denominator**: Total patients x 100<br>**Exclusion**: -<br>**Performance standard**: 75% |
| 215 | National Hospice and Palliative Care Organization (NHPCO), 2006<br>Brown University, 2006 | Family evaluation of hospice care: Symptom management<br>Questions:<br>B9: While under the care of hospice, did the patient have any feelings of anxiety or sadness?<br>B10: How much help in dealing with these feelings did the patient receive?<br>Outcome | **Numerator**: Those who received too much or too little help concerning anxiety/sadness<br>**Denominator**: Those who experience anxiety/sadness<br>**Exclusion**: Patients who are not enrolled in a hospice program or have disenrolled from a hospice program. Live discharged are excluded<br>**Performance standard**: - |
| 216 | NEW Miyashita, 2008<br>Sato, 2008 | Symptom control: Presence or absence of delirium or agitation.<br>Outcome | **Numerator:** Number of patients for whom this indicator was documented on admission or within the last 2 weeks of the hospitalization<br>**Denominator:** All patients who died (retrospectively identified)<br>**Exclusion: -**<br>**Performance standard: -** |
| 217 | NEW Miyashita, 2008<br>Sato, 2008 | Symptom control: Physician's prescription order for delirium or agitation.<br>Process | **Numerator:** Number of patients for whom this indicator was documented on admission or within the last 2 weeks of the hospitalization<br>**Denominator:** All patients who died (retrospectively identified)<br>**Exclusion: -**<br>**Performance standard: -** |
| 218 | NEW Miyashita, 2008<br>Sato, 2008 | Psychosocial and spiritual concerns: Degree and content of patient's anxiety.<br>Outcome | **Numerator:** Number of patients for whom this indicator was documented on admission or within the last 2 weeks of the hospitalization<br>**Denominator:** All patients who died (retrospectively identified)<br>**Exclusion: -**<br>**Performance standard: -** |

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| 219 | NEW Schenck, 2010 | Psychological Aspects of Care: For patients who screened positive for anxiety, the percent who receive treatment within two weeks of diagnosis.<br>Process | **Numerator:** Number of patients with (0<=Time<=14 days and anxiety treatment="Y") (Anxiety treatment time = date of treatment – anxiety assessment date)<br>**Denominator:** # patients with anxiety screening=Y<br>**Exclusion: -**<br>**Performance standard: -** |
| 220 | NEW Lorenz, 2009 | Delirium IF a hospitalized patient with cancer aged >65 years or with advanced cancer has delirium THEN there should be an assessment for the presence or absence of at least 1 of the following potential causes and their association with delirium: medication effects, central nervous system disease, infection, and metabolic processes.<br>Process | **Numerator**: -<br>**Denominator**: -<br>**Exclusion**: -<br>**Performance standard**: - |
| 221 | NEW Claessen, 2011 | Care for psychosocial well-being of patients: Percentage of patients with anxiety<br>Anxiety is a common symptom for many patients in the palliative phase, as a reaction to their illness and the prospect of approaching death. Anxiety can be influenced by pharmacological and non-pharmacological interventions (e.g. psychosocial support).<br>Outcome | **Numerator:** The number of patients with an anxiety score of 4 or above on the NRS (average over 3 days)<br>**Denominator:** The total number of patients for whom this indicator is measured.<br>**Exclusion:** Patients with moderate to (very) severe cognitive impairments, young children, psychiatric and/or confused patients, and comatose and deeply sedated patients<br>**Performance standard: -** |

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| **200** | NEW van der Ploeg, 2008<br>This indicator suits domain 2,3,4 and 8. | IF a vulnerable elder dies with a progressive incurable disease (for example metastatic cancer, or dementia) THEN there should be evidence within 6 months prior to death that they received a comprehensive assessment including:<br>• Pain;<br>• Anxiety, depression;<br>• Vomiting and dyspnea;<br>• Spiritual and existential concerns;<br>• Caregiver burdens/need for practical assistance;<br>• Wishes concerning medical treatment and care at the end of life;<br>A discussion about and if possible the determination of a surrogate decision maker.<br>Process | **Numerator: -**<br>**Denominator: -**<br>**Exclusion: -**<br>**Performance standard: -** |
| 222 | NEW Schenck, 2010 | Psychological Aspects of Care: For patients who screened positive for depression, the percent who received further assessment, counseling or medication treatment.<br>Process | **Numerator:** Number of patients with depression further assessment=”Y”<br>**Denominator:** # patients with depression screening=Yes<br>**Exclusion: -**<br>**Performance standard: -** |
| 223 | NEW Schenck, 2010 | Psychological Aspects of Care: For patients diagnosed with depression, the percent who receive treatment within two weeks of diagnosis.<br>Process | **Numerator:** Number of patients with (0<=Depression Treatment Time<=14 days and depression treatment=”Y”)<br>**Denominator:** # patients with depression diagnosis =Y<br>(Depression treatment time = date of treatment – depression diagnosis date)<br>**Exclusion: -**<br>**Performance standard: -** |
| 224 | NEW Lorenz, 2009 | Depression and psychosocial distress IF depression is diagnosed in a cancer patient, THEN a treatment plan for depression should be documented.<br>Process | **Numerator**: -<br>**Denominator**: -<br>**Exclusion**: -<br>**Performance standard**: - |

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| 225 | $^{\text{NEW}}$ Lorenz, 2009 | Depression and psychosocial distress IF a patient with cancer is treated for depression, THEN response to therapy should be documented within 6 weeks.<br>Process | **Numerator**: -<br>**Denominator**: -<br>**Exclusion**: -<br>**Performance standard**: - |
| 226 | $^{\text{NEW}}$ Claessen, 2011 | Care for psychosocial well-being of patients: Percentage of patients who feel depressed<br>Depression is a common symptom in the palliative phase, and can be influenced most by non-pharmacological interventions (listening to them), and to a lesser extent by pharmacological interventions (e.g. antidepressants).<br>Outcome | **Numerator:** The number of patients with a feeling depressed score of 4 or above on the NRS (average over 3 days).<br>**Denominator:** The total number of patients for whom this indicator is measured.<br>**Exclusion:** Patients with moderate to (very) severe cognitive impairments, young children, psychiatric and/or confused patients, and comatose and deeply sedated patients<br>**Performance standard: -** |
| 227 | Peruselli, 1997 | Palliative care services must meet the physical, psychological, social and spiritual needs of patients.<br>Outcome | **Numerator**: Number of patients with global scores for cognitive status (TIQ scale) dropped after 8 days of care (if initial score on the same scale > 25)<br>**Denominator**: Total patients x 100<br>**Exclusion**: -<br>**Performance standard**: 75% |
| 228 | Peruselli, 1997 | Palliative care services must meet the physical, psychological, social and spiritual needs of patients.<br>Outcome | **Numerator**: Number of patients with global scores for cognitive status (TIQ scale) not increased over initial score during final week of care (if initial score on the same scale > 25)<br>**Denominator**: Total patients x 100<br>**Exclusion**: -<br>**Performance standard**: 75% |
| 229 | National Hospice and Palliative Care Organization (NHPCO), 2006 Brown University, 2006 | Attend to family needs (Family evaluation of hospice care)<br>Questions:<br>E2: Did you have as much contact about your religious or spiritual beliefs as you wanted?<br>E3: How much emotional support did the hospice team provide to you prior to the patient's death?<br>E4: How much emotional support did the hospice team provide to you after the patient's death?<br>Outcome | **Numerator**: Sum of 1 response to survey instrument by family member of deceased patient<br>**Denominator**: Number of items (=3)<br>**Exclusion**: Patients who are not enrolled in a hospice program or have disenrolled from a hospice program. Live discharged are excluded<br>**Performance standard**: - |

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| 230 | Yabroff, 2004 | Percentage of patients within and among health facilities or systems with evidence for ongoing quality of life assessment reflected in the treatment plan.<br>Process | **Numerator**: -<br>**Denominator**: -<br>**Exclusion**: -<br>**Performance standard**: - |
| 231 | Peruselli, 1997 | Palliative care services must meet the physical, psychological, social and spiritual needs of patients.<br>Outcome | **Numerator**: Number of patients with global scores for emotional status (TIQ scale) dropped after 8 days of care (if initial score on the same scale > 25)<br>**Denominator**: Total patients x 100<br>**Exclusion**: -<br>**Performance standard**: 75% |
| 232 | Peruselli, 1997 | Palliative care services must meet the physical, psychological, social and spiritual needs of patients.<br>Outcome | **Numerator**: Number of patients with global scores for emotional status (TIQ scale) not increased over initial score during final week of care (if initial score on the same scale > 25)<br>**Denominator**: Total patients x 100<br>**Exclusion**: -<br>**Performance standard**: 75% |
| 233 | Peruselli, 1997 | Palliative care services must meet the physical, psychological, social and spiritual needs of patients.<br>Outcome | **Numerator**: Number of patients with global scores for therapy impact index (= comprising functional impairment, emotional status, cognitive status, social interaction TIQ scales) dropped after 8 days of care (if initial score on the same scale > 25)<br>**Denominator**: Total patients x 100<br>**Exclusion**: -<br>**Performance standard**: 75% |
| 234 | Peruselli, 1997 | Palliative care services must meet the physical, psychological, social and spiritual needs of patients.<br>Outcome | **Numerator**: Number of patients with global scores for therapy impact index (= comprising functional impairment, emotional status, cognitive status, social interaction TIQ scales) not increased over initial score during final week of care (if initial score on the same scale > 25)<br>**Denominator**: Total patients x 100<br>**Exclusion**: -<br>**Performance standard**: 75% |
| 235 | Peruselli, 1997 | Palliative care services must meet the physical, psychological, social and spiritual needs of patients.<br>Outcome | **Numerator**: Number of patients with score for communication between patient en family (STAS item) dropped after 8 days of care (if initial score >0)<br>**Denominator**: Total patients x 100<br>**Exclusion**: -<br>**Performance standard**: 75% |
| 236 | Peruselli, 1997 | Palliative care services must meet the physical, psychological, social and spiritual needs of patients.<br>Outcome | **Numerator**: Number of patients with score for communication between patient en family (STAS item) of 0-1 during final week of life<br>**Denominator**: Total patients x 100<br>**Exclusion**: -<br>**Performance standard**: 75% |

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| 237 | Twaddle, 2007 | Psychosocial assessment<br>All patients were expected to have a psychosocial assessment (i.e. a formal psychosocial assessment conducted by a psychologist, social worker, psychiatrist or other expert) completed within 1 year prior or 4 days after admission.<br>Process | **Numerator**: -<br>**Denominator**: -<br>**Exclusion**: -<br>**Performance standard**: 90% |
| 238 | $^{\text{NEW}}$ Miyashita, 2008 | Psychosocial and spiritual concerns: Patient's preference of daily living.<br>Outcome | **Numerator:** Number of patients for whom this indicator was documented on admission or within the last 2 weeks of the hospitalization<br>**Denominator:** All patients who died (retrospectively identified)<br>**Exclusion: -**<br>**Performance standard: -** |
| 239 | Keay, 1994 | Psychological or social support is documented in the patient's medical record<br>Process | **Numerator**: -<br>**Denominator**: -<br>**Exclusion**: Patient death within a few hours of being declared terminally ill; patient cognitively impaired *and* family or friends are not reasonably available<br>**Performance standard**: > 80% |
| **Domain 4: Social aspects of care (15 indicators)** | | | |
| | **Reference/ year** | **Description/type of indicator** | **Numerator/Denominator/Exclusion/ Performance standard** |
| 240 | Mularski, 2006 | Documentation of offering of psychosocial support within the first 72 hours of admission to the ICU.<br>Process | **Numerator**: Total number of patients in the ICU for > 72 hours with psychosocial support offered to the patient or family by any team member<br>**Denominator**: Total number of patients in the ICU for > 72 hours<br>**Exclusion**: Comatose patients (e.g. Glasgow Coma Score of 2 or 3) with no family member of friend identified<br>**Performance standard**: - |
| 241 | Nelson, 2006 | Social work support: percentage of patients with documentation that social work support was offered to the patient/family.<br>Process | **Numerator**: Number of patients with documentation that social work support was offered to the patient/family<br>**Denominator**: Total number of patients with ICU length of stay ≥ 3 days<br>**Exclusion**: -<br>**Performance standard**: - |

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| 242 | Lorenz, 2007<br>NEW van der Ploeg, 2008 | Caregiver stress<br>IF a VE is a caregiver for a spouse, significant other , or dependent who is terminally ill or has very limited function, THEN the VE should be assessed for caregiver financial, physical, and emotional stress, BECAUSE caregiver burden is substantial in these situations and associated with poor outcomes.<br>Process | **Numerator**: -<br>**Denominator**: -<br>**Exclusion**: -<br>**Performance standard**: - |
| 243 | NEW Miyashita, 2008 | Family care: Care strategy for family<br>Process | **Numerator:** Number of patients for whom this indicator was documented on admission or within the last 2 weeks of the hospitalization<br>**Denominator:** All patients who died (retrospectively identified)<br>**Exclusion: -**<br>**Performance standard: -** |
| 244 | NEW Miyashita, 2008 | Psychosocial and spiritual concerns: Coordination of social resources when patient had no family or friends.<br>Process | **Numerator:** Number of patients for whom this indicator was documented on admission or within the last 2 weeks of the hospitalization<br>**Denominator:** All patients who died (retrospectively identified)<br>**Exclusion: -**<br>**Performance standard: -** |
| **200** | NEW van der Ploeg, 2008<br>This indicator suits domain 2,3,4 and 8. | IF a vulnerable elder dies with a progressive incurable disease (for example metastatic cancer, or dementia) THEN there should be evidence within 6 months prior to death that they received a comprehensive assessment including:<br>• Pain;<br>• Anxiety, depression;<br>• Vomiting and dyspnea;<br>• Spiritual and existential concerns;<br>• Caregiver burdens/need for practical assistance;<br>• Wishes concerning medical treatment and care at the end of life;<br>A discussion about and if possible the determination of a surrogate decision maker.<br>Process | **Numerator: -**<br>**Denominator: -**<br>**Exclusion: -**<br>**Performance standard: -** |

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| 245 | $^{\text{NEW}}$ Quality Markers, 2009 | QM for primary care: They have mechanisms in place to assess and document the needs of carers of those approaching the end of life (Royal College of General Practicioners' Supporting Carers).<br>Outcome | Proportion of individuals whose carer is recorded<br>**Numerator**: -<br>**Denominator**: -<br>**Exclusion**: -<br>**Performance standard**: - |
| 246 | $^{\text{NEW}}$ Quality Markers, 2009 | QM for primary care: They have mechanisms in place to assess and document the needs of carers of those approaching the end of life (Royal College of General Practicioners' Supporting Carers).<br>Process | Proportion of carers who have been referred to a carer's assessment and whose needs have been recorded<br>**Numerator**: -<br>**Denominator**: -<br>**Exclusion**: -<br>**Performance standard**: - |
| 247 | $^{\text{NEW}}$ ELCQuA, 2011 | The needs and preferences of carers are assessed and recorded.<br>Process | Proportion of deaths where the patient/service user had a recorded carer<br>**Numerator:** Number of patients who died whose carer was recorded, including n/a.<br>**Denominator:** Total deaths for same time period<br>**Exclusion:** -<br>**Performance standard:** Carer's assessments undertaken for all appropriate cases<br>Proportion of carers referred for a carer's assessment<br>**Numerator:** Number of carers who have been referred for a carer's assessment<br>**Denominator:** Total number of carers<br>**Exclusion:** -<br>**Performance standard:** Carer's assessments undertaken for all appropriate cases<br>Proportion of carers referred for assessment actually receiving an assessment<br>**Numerator:** Number of carers whose needs have been recorded<br>**Denominator:** Number of carers referred for assessment<br>**Exclusion:** -<br>**Performance standard:** Carer's assessments undertaken for all appropriate cases |
| 248 | Peruselli, 1997 | Support provided to patient and family also includes home visits by voluntary workers.<br>Process | **Numerator**: Number of patients who have had home visits by voluntary workers<br>**Denominator**: Population served x 100<br>**Exclusion**: -<br>**Performance standard**: 30% |

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| 249 | Peruselli, 1997 | Palliative care services must meet the physical, psychological, social and spiritual needs of patients.<br>Outcome | **Numerator**: Number of patients with global scores for social interaction (TIQ scale) dropped after 8 days of care (if initial score on the same scale > 25)<br>**Denominator**: Total patients x 100<br>**Exclusion**: -<br>**Performance standard**: 75% |
| 250 | Peruselli, 1997 | Palliative care services must meet the physical, psychological, social and spiritual needs of patients.<br>Outcome | **Numerator**: Number of patients with global scores for social interaction (TIQ scale) not increased over initial score during final week of care (if initial score on the same scale > 25)<br>**Denominator**: Total patients x 100<br>**Exclusion**: -<br>**Performance standard**: 75% |
| 251 | $^{NEW}$ Miyashita, 2008<br>Sato, 2008 | Family care: Configuration of family relationships.<br>Process | **Numerator:** Number of patients for whom this indicator was documented on admission or within the last 2 weeks of the hospitalization<br>**Denominator:** All patients who died (retrospectively identified)<br>**Exclusion: -**<br>**Performance standard: -** |
| 252 | $^{NEW}$ Sato, 2008 | Family care: Family's insight of disease.<br>Outcome | **Numerator:** Number of patients for whom this indicator was documented on admission or within the last 2 weeks of the hospitalization<br>**Denominator:** All patients who died (retrospectively identified)<br>**Exclusion: -**<br>**Performance standard: -** |
| 253 | $^{NEW}$ Sato, 2008 | Family care: Discussion with family about goals of care.<br>Process | **Numerator:** Number of patients for whom this indicator was documented on admission or within the last 2 weeks of the hospitalization<br>**Denominator:** All patients who died (retrospectively identified)<br>**Exclusion: -**<br>**Performance standard: -** |
| **Domain 5: Spiritual, religious and existential aspects of care (6 indicators)** | | | |
| | **Reference/ year** | **Description/type of indicator** | **Numerator/Denominator/Exclusion/ Performance standard** |
| 254 | Nelson, 2006,<br>Mularski, 2006 | Spiritual support: percentage of patients with documentation that spiritual support was offered to the patient /family.<br>Process | **Numerator**: Number of patients with documentation that spiritual support was offered to the patient/family<br>**Denominator**: Total number of patients with ICU length of stay ≥ 3 days<br>**Exclusion**: patients with no family members visiting the patient during the ICU stay<br>**Performance standard**: - |
| 255 | $^{NEW}$ Miyashita, 2008<br>Sato, 2008 | Psychosocial and spiritual concerns: Patient's religion.<br>Outcome | **Numerator:** Number of patients for whom this indicator was documented on admission or within the last 2 weeks of the hospitalization<br>**Denominator:** All patients who died (retrospectively identified)<br>**Exclusion: -**<br>**Performance standard: -** |

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| 256 | $^{NEW}$ Schenck, 2010 | Spiritual Aspects of Care: Percent of patients with chart documentation of a discussion of spiritual concerns.<br>Outcome | **Numerator:** Number of patients with spiritual discussion = “Y”<br>**Denominator:** Total number of patients<br>**Exclusion: -**<br>**Performance standard: -** |
| 257 | $^{NEW}$ Miyashita, 2008 | Psychosocial and spiritual concerns: Emotional reaction to explanation of medical condition.<br>Outcome | **Numerator:** Number of patients for whom this indicator was documented on admission or within the last 2 weeks of the hospitalization<br>**Denominator:** All patients who died (retrospectively identified)<br>**Exclusion: -**<br>**Performance standard: -** |
| 258 | $^{NEW}$ Claessen, 2011 | Care for spiritual well-being of patients: Percentage of relatives who indicate that the patient died peacefully<br>If patients die peacefully, this can indicate that in this respect their spiritual needs were met.<br>Outcome | **Numerator:** The number of relatives who indicate that their relative died peacefully<br>**Denominator:** The total number of relatives among whom this quality indicator was measured<br>**Exclusion: -**<br>**Performance standard:** |
| 259 | $^{NEW}$ Claessen, 2011 | Care for spiritual well-being of patients: Percentage of relatives who indicate that the patient had accepted her/his approaching death.<br>If patients accept their approaching death, this can indicate that their spiritual needs were met.<br>Outcome | **Numerator:** The number of relatives who indicate that their relative had accepted approaching death<br>**Denominator:** The total number of relatives among whom this quality indicator was measured<br>**Exclusion: -**<br>**Performance standard:** |
| **Domain 6: Cultural aspects of care (1 indicator)** | | | |
| | **Reference/ year** | **Description/type of indicator** | **Numerator/Denominator/Exclusion/ Performance standard** |
| 260 | $^{NEW}$ Miyashita, 2008 | Family care: Family’s preference of explanation of medical condition.<br>Outcome | **Numerator**: Number of patients for whom this indicator was documented on admission or within the last 2 weeks of the hospitalization<br>**Denominator**: All patients who died (retrospectively identified)<br>**Exclusion**: -<br>**Performance standard**: - |
| **Domain 7: Care for the imminently dying patient (26 indicators)** | | | |
| | **Reference/ year** | **Description/type of indicator** | **Numerator/Denominator/Exclusion/ Performance standard** |
| 261 | Earle, 2006 | Proportion receiving chemotherapy in the last 14 days of life.<br>Process | **Numerator**: Patients who died from cancer and received chemotherapy in the last 14 days of life<br>**Denominator**: Patients who died from cancer<br>**Exclusion**: -<br>**Performance standard**: < 10% |

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| 262 | Earle, 2006 | Proportion with more than one emergency room (ER) visit in the last 30 days of life.<br>Process | **Numerator**: Patients who died from cancer and had > 1 ER visit in the last 30 days of life<br>**Denominator**: Patients who died from cancer<br>**Exclusion**: -<br>**Performance standard**: < 4% |
| 263 | NEW Grunfeld, 2008 | Frequency of ER visits<br>High number of emergency room visits near death may indicate poor quality care.<br>Outcome | **Numerator:** Number of cases with more than 1 ER visit in the last 30 days<br>**Denominator:** entire cohort<br>**Exclusion: -**<br>**Performance standard: -**<br>**Numerator:** Number of ER visits in the last 30 days averaged across entire cohort<br>**Denominator: -**<br>**Exclusion: -**<br>**Performance standard: -**<br>**Numerator:** Sum of ER visits across entire cohort<br>**Denominator:** The sum of available days (i.e., days out of hospital) across entire cohort)<br>**Exclusion: -**<br>**Performance standard: -** |
| 264 | Earle, 2006 | Proportion with more than one hospitalization in the last 30 days of life.<br>Process | **Numerator**: Patients who died from cancer and had > 1 hospitalization in the last 30 days of life<br>**Denominator**: Patients who died from cancer<br>**Exclusion**: -<br>**Performance standard**: < 4% |
| 265 | Earle, 2006 | Proportion admitted to the ICU in the last 30 days of life.<br>Process | **Numerator**: Patients who died from cancer and were admitted to the ICU in the last 30 days of life<br>**Denominator**: Patients who died from cancer<br>**Exclusion**: -<br>**Performance standard**: < 4% |
| 266 | NEW Grunfeld, 2008 | ICU stays near the end of life<br>Hospital stays in the terminal period of cancer may indicate poor quality care.<br>Outcome | **Numerator:** Number of cases with one or more ICU admissions in the last 30 days<br>**Denominator:** Entire cohort<br>**Exclusion: -**<br>**Performance standard: -** |
| 267 | NEW Grunfeld, 2008 | Enrollment in palliative care within 3 days of death<br>A high proportion may indicate poor quality care. Palliative care should be accessible to all patients and families with a cancer diagnosis, in a timely manner, throughout the entire duration of their disease.<br>Process | **Numerator:** Number of cases enrolled in palliative care within three days prior to death<br>**Denominator:** All cases enrolled in palliative care<br>**Exclusion: -**<br>**Performance standard: -** |

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| 268 | NEW Miyashita, 2008 | Decision making and preference of care: Time of patient’s enrollment in palliative care program and documented medical history.<br>Outcome | **Numerator**: Number of patients for whom this indicator was documented on admission or within the last 2 weeks of the hospitalization<br>**Denominator**: All patients who died (retrospectively identified)<br>**Exclusion**: -<br>**Performance standard**: - |
| 269 | Mularski, 2006 | Documentation of a protocol for provision of analgesia and sedation during terminal withdrawal of mechanical ventilation.<br>Structure | **Numerator**: Presence of a protocol that can be applied in settings of terminal withdrawal of mechanical ventilation<br>**Denominator**: ICU<br>**Exclusion**: -<br>**Performance standard**: - |
| 270 | Peruselli, 1997 | Home palliative care services must ensure continuous care for the patient until the final moments of life, and for the family after the patient’s death by helping to deal with the mourning process.<br>Process | **Numerator**: Number of families who have received home visits on the day of patient’s death<br>**Denominator**: Population served x 100<br>**Exclusion**: -<br>**Performance standard**: 90% |
| 271 | Peruselli, 1997 | Home palliative care services must ensure continuous care for the patient until the final moments of life, and for the family after the patient’s death by helping to deal with the mourning process.<br>Process | **Numerator**: Number of families who have received home visits in the days following patient’s death to provide support during the mourning process<br>**Denominator**: Population served x 100<br>**Exclusion**: -<br>**Performance standard**: 90% |
| 272 | NEW Grunfeld, 2008 | Time and location of care<br>The ideal is assumed to be clinician visits that are more frequent as death approaches.<br>Process | **Numerator:** Sum of home and office visits for the entire cohort in last two weeks<br>**Denominator:** Sum of home and office visits for the entire cohort in last six months<br>**Exclusion: -**<br>**Performance standard: -** |
| 273 | Keay,1994 | Follow-up bereavement counseling is offered by the physician.<br>Process | **Numerator**: -<br>**Denominator**: -<br>**Exclusion**: -<br>**Performance standard**: - |

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| 274 | National Hospice and Palliative Care Organization (NHPCO), 2006<br>Brown University, 2006 | Inform and communicate about patient (Family evaluation of hospice care)<br><br>Questions:<br>D5: How often did the hospice team keep you or other family members informed about the patient's condition?<br>D7: Would you have wanted more information about what to expect while the patient was dying?<br><br>Process | **Numerator**: Sum of 1 response to survey instrument by family member of deceased patient<br>**Denominator**: Number of items (=2)<br>**Exclusion**: Patients who are not enrolled in a hospice program or have disenrolled from a hospice program. Live discharged are excluded<br>**Performance standard**: - |
| 275 | National Hospice and Palliative Care Organization (NHPCO), 2006<br>Brown University, 2006 | Provide information about symptoms (Family evaluation of hospice care)<br><br>Questions:<br>B4: Did you want more information than you got about the medicines used to manage the patient's pain?<br>B8: Did you want more information than you got about what was being done for the patient's trouble with breathing?<br><br>Process | **Numerator**: Sum of 1 response to survey instrument by family member of deceased patient<br>**Denominator**: Number of items (=2)<br>**Exclusion**: Patients who are not enrolled in a hospice program or have disenrolled from a hospice program. Live discharged are excluded<br>**Performance standard**: - |
| 276 | Lorenz, 2007<br><br>$^{NEW}$ van der Ploeg, 2008 | Bereavement<br><br>IF a VE's spouse or significant other dies, THEN the VE should be assessed for depression or thoughts of suicidality within 6 months, BECAUSE bereaved persons are at high risk of poor outcomes.<br><br>Process | **Numerator**: -<br>**Denominator**: -<br>**Exclusion**: -<br>**Performance standard**: - |
| 277 | $^{NEW}$ Quality Markers, 2009 | QM for primary care:<br>They collate information of the quality of care provided to individuals after their death for audit purposes (e.g. using a tool such as the After Death Analysis from the Gold Standards Framework).<br><br>Process | Proportion of carers and family members who receive support following the death of a patient<br>**Numerator**: -<br>**Denominator**: -<br>**Exclusion**: -<br>**Performance standard**: - |

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| 278 | $^{\text{NEW}}$ ELCQuA, 2011 | Relatives, carers and friends of the deceased, including other residents/patients and children, have access to effective bereavement services.<br>Process | **Numerator:** Number of providers meeting 75% of NICE bereavement standards<br>**Denominator:** Total number of providers<br>**Exclusion:** -<br>**Performance standard:** Standards in NICE Supportive and Palliative Care Guidance are fully met by all relevant providers, and all care homes have policies in place to ensure other residents are supported following death |
| 279 | $^{\text{NEW}}$ ELCQuA, 2011 | Verification of death and care after death is sensitively delivered in line with best practice.<br>Process | **Numerator:** Number of deaths using the care after death module of the LCP or equivalent<br>**Denominator:** Total number of deaths<br>**Exclusion:** -<br>**Performance standard:** - |
| 280 | $^{\text{NEW}}$ Quality Markers, 2009 | QM for primary care:<br>They have mechanisms in place to assess and document the needs of those approaching the end of life (e.g. use of the Gold Standards Framework or equivalent), and to discuss, record and, (where appropriate) communicate the wishes and preferences of those approaching the end of life (advance care planning).<br>Outcome | Proportion of patients who die in their preferred place for care<br>**Numerator**: -<br>**Denominator**: -<br>**Exclusion**: -<br>**Performance standard**: - |
| 281 | $^{\text{NEW}}$ Quality Markers, 2009 | QM for primary care: They collate information of the quality of care provided to individuals after their death for audit purposes (e.g. using a tool such as the After Death Analysis from the Gold Standards Framework).<br>Outcome | Proportion of individuals who die in their preferred place<br>**Numerator**: -<br>**Denominator**: -<br>**Exclusion**: -<br>**Performance standard**: - |
| 282 | $^{\text{NEW}}$ Quality Markers, 2009 | QM for district/community nursing services.<br>They have mechanisms in place to assess and document the needs of those approaching the end of life (e.g. use of the Gold Standards Framework or equivalent), and to discuss, record and, (where appropriate) communicate the wishes and preferences of those approaching the end of life (advance care planning).<br>Outcome | Proportion of patients who die in their preferred place for care<br>**Numerator**: -<br>**Denominator**: -<br>**Exclusion**: -<br>**Performance standard**: - |

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| 283 | $^{\text{NEW}}$ Claessen, 2011 | Generic aspects: Percentage of patients who died in the location of their preference<br>Patients have the right to die wherever they wish. The patient's wishes therefore prevail.<br>Outcome | **Numerator**: The number of relatives who indicate that the patient died in the location of his/her preference<br>**Denominator**: The total number of relatives among whom this quality indicator was measured<br>**Exclusion**: -<br>**Performance standard**: - |
| **284** | $^{\text{NEW}}$ ELCQuA, 2011<br>This indicator suits domain 7 and 8. | Individuals are offered an advance care plan.<br>Process/Outcome | **Numerator:** Number of patients who died who were registered to have an advance care plan in place plus number offered a care plan but without a plan in place.<br>**Denominator:** Total deaths.<br>**Exclusion:** -<br>**Performance standard:** All patients/service users requiring end of life care or approaching end of life are offered advance care planning conversations<br>**Numerator:** Number dying in preferred place of death.<br>**Denominator:** Total number dying with an advance care plan in place.<br>**Exclusion**: -<br>**Performance standard**: -<br>**Numerator:** Number of patients who died in their own home or care home.<br>**Denominator:** Total deaths for same time period<br>**Exclusion**: -<br>**Performance standard**: -<br>**Numerator:** Number of deaths in hospital within 3 days of admission by PCT or acute site.<br>**Denominator:** Total deaths in same catchment for same time period<br>**Exclusion**: -<br>**Performance standard**: - |
| 285 | $^{\text{NEW}}$ Quality Markers, 2009 | QM for primary care:<br>They collate information of the quality of care provided to individuals after their death for audit purposes (e.g. using a tool such as the After Death Analysis from the Gold Standards Framework).<br>Outcome | Proportion of individuals who die at home.<br>**Numerator**: -<br>**Denominator**: -<br>**Exclusion**: -<br>**Performance standard**: - |
| **Domain 8: Ethical and legal aspects of care (45 indicators)** | | | |
| | **Reference/ year** | **Description/type of indicator** | **Numerator/Denominator/Exclusion/ Performance standard** |
| 286 | Keay, 1994 | Interventions not wanted by the patient are not performed.<br>Process | **Numerator**: -<br>**Denominator**: -<br>**Exclusion**: Conflicting patient directives<br>**Performance standard**: > 80% |

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| 287 | Lorenz, 2007 | Decisions about life-sustaining treatment<br>IF a VE has documented treatment preferences to withhold or withdraw life-sustaining treatment (e.g., DNR order, no tube feeding, no hospital transfer), THEN these treatment preferences should be followed, BECAUSE medical care should aim to be consistent with a patient's preferences.<br>Process | **Numerator**: -<br>**Denominator**: -<br>**Exclusion**: -<br>**Performance standard**: - |
| 288 | NEW Miyashita, 2008<br>Sato, 2008 | Decision making and preference of care: Patient's preference of place of care.<br>Outcome | **Numerator:** Number of patients for whom this indicator was documented on admission or within the last 2 weeks of the hospitalization<br>**Denominator:** All patients who died (retrospectively identified)<br>**Exclusion: -**<br>**Performance standard: -** |
| 289 | NEW Miyashita, 2008<br>Sato, 2008 | Decision making and preference of care: Patient's insight of disease.<br>Outcome | **Numerator:** Number of patients for whom this indicator was documented on admission or within the last 2 weeks of the hospitalization<br>**Denominator:** All patients who died (retrospectively identified)<br>**Exclusion: -**<br>**Performance standard: -** |
| 290 | NEW Miyashita, 2008<br>Sato, 2008 | Family care: Family's preferred place of care.<br>Outcome | **Numerator:** Number of patients for whom this indicator was documented on admission or within the last 2 weeks of the hospitalization<br>**Denominator:** All patients who died (retrospectively identified)<br>**Performance standard: -** |
| 291 | NEW Miyashita, 2008<br>Sato, 2008 | Family care: Family's preferences or expectations.<br>Outcome | **Numerator:** Number of patients for whom this indicator was documented on admission or within the last 2 weeks of the hospitalization<br>**Denominator:** All patients who died (retrospectively identified)<br>**Performance standard: -** |
| 292 | NEW Quality Markers, 2009 | QM for primary care: They (GP practices) have mechanisms in place to assess and document the needs of those approaching the end of life (e.g. use of the Gold Standards Framework or equivalent), and to discuss, record and, (where appropriate) communicate the wishes and preferences of those approaching the end of life (advance care planning).<br>Outcome | Proportion of individuals whose preferred place for care has been recorded<br>**Numerator**: -<br>**Denominator**: -<br>**Exclusion**: -<br>**Performance standard**: - |

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| 293 | NEW Quality Markers, 2009 | QM for district/community nursing services.<br>They have mechanisms in place to assess and document the needs of those approaching the end of life (e.g. use of the Gold Standards Framework or equivalent), and to discuss, record and, (where appropriate) communicate the wishes and preferences of those approaching the end of life (advance care planning).<br>Outcome | Proportion of individuals whose preferred place for care has been recorded<br>**Numerator**: -<br>**Denominator**: -<br>**Exclusion**: -<br>**Performance standard**: - |
| **200** | NEW van der Ploeg, 2008<br>This indicator suits domain 2,3,4 and 8. | IF a vulnerable elder dies with a progressive incurable disease (for example metastatic cancer, or dementia) THEN there should be evidence within 6 months prior to death that they received a comprehensive assessment including:<br>• Pain;<br>• Anxiety, depression;<br>• Vomiting and dyspnea;<br>• Spiritual and existential concerns;<br>• Caregiver burdens/need for practical assistance;<br>• Wishes concerning medical treatment and care at the end of life;<br>A discussion about and if possible the determination of a surrogate decision maker.<br>Process | **Numerator: -**<br>**Denominator: -**<br>**Exclusion: -**<br>**Performance standard: -** |
| 294 | Mularski, 2006 | Assessment within 24 hours of admission of the patient's capacity to make decisions.<br>Process | **Numerator**: Total number of patients in the ICU with documentation of decisional capacity made within 24 hours of admission<br>**Denominator**: Total number of patients in the ICU for > 24 hours<br>**Exclusion**: -<br>**Performance standard**: - |
| 295 | Nelson, 2006, Mularski, 2006 | Medical decision maker: Percentage of patients with documentation of status of identification of health care proxy (or other appropriate surrogate).<br>Process | **Numerator**: Number of patients with documentation of status of identification of health care proxy (or other appropriate surrogate)<br>**Denominator**: Total number of patients admitted to the ICU within the last 24 hours<br>**Exclusion**: -<br>**Performance standard**: - |

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| 296 | $^{\text{NEW}}$ Miyashita, 2008<br>Sato, 2008 | Family care: Key person involved in patient care.<br>Outcome | **Numerator:** Number of patients for whom this indicator was documented on admission or within the last 2 weeks of the hospitalization<br>**Denominator:** All patients who died (retrospectively identified)<br>**Exclusion: -**<br>**Performance standard: -** |
| 297 | $^{\text{NEW}}$ Schenck, 2010 | Ethical and legal aspects of care: Percent of patients with contact information for surrogate decision maker in the chart or documentation that there is no surrogate.<br>Outcome | **Numerator:** Number of patients with surrogate contact info =”Y” or Discussion of no surrogate = “Y”<br>**Denominator:** Number of Patients<br>**Exclusion: -**<br>**Performance standard: -** |
| 298 | $^{\text{NEW}}$ Schenck, 2010 | Ethical and legal aspects of care: Percent of patients with impaired decision making (dementia, coma or other impairment) that have documentation of surrogate decision maker in chart within 2 days of recognition of impaired decision making.<br>Outcome | **Numerator:** Number of patients with (0≤Surrogate document time≤2days) and (Dementia=”Y” or Confused-sedated-nonverbal=”Y”) (Surrogate date = Date of documentation if chart has a surrogate decision maker, or date of documentation of no surrogate if chart contains contact info of surrogate or discussion of no surrogate is recorded; Surrogate document time = surrogate date–admission date)<br>**Denominator:** Number of patients with dementia=”Y” or confused-sedated-nonverbal=”Y”<br>**Exclusion: -**<br>**Performance standard: -** |
| 299 | Nelson, 2006, Mularski, 2006 | Advance directive: percentage of patients with documentation of advance directive status on or before day 1 of the ICU admission.<br>Process | **Numerator:** Number of patients who have documentation of advance directive status on or before day 1of the ICU admission<br>**Denominator:** Total number of patients with an ICU length of stay > 5 days<br>**Exclusion:** Patients discharged (or transferred out of the ICU) on or before day 1 of ICU admission<br>Patients expired on or before day 1 of ICU admission<br>Patients with decisional capacity<br>**Performance standard:** - |
| 300 | Nelson, 2006 | Resuscitation status: percentage of patients with documentation of resuscitation status.<br>Process | **Numerator:** Number of patients with documentation of resuscitation status<br>**Denominator:** Total number of patients admitted to the ICU within the last 24 hours<br>**Exclusion**: -<br>**Performance standard**: - |
| 301 | Keay, 1994 | Documentation of patients wishes or advance directive is present.<br>Process | **Numerator**: -<br>**Denominator**: -<br>**Exclusion**: Patient was always incapacitated and without advance directive or legal proxy<br>**Performance standard**: 100% |

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| 302 | Lorenz, 2007 | ACP documented<br>ALL VEs should have in the outpatient chart patient's surrogate decision maker, or documentation of a discussion to identify or search for a surrogate decision maker, BECAUSE, advance directives and discussions about surrogate decisions makers facilitate identification of surrogate decision makers and decision making on behalf of a patient who has lost decision-making capacity.<br>Process | **Numerator**: -<br>**Denominator**: -<br>**Exclusion**: -<br>**Performance standard**: - |
| 303 | Lorenz, 2007 | Advance directive and surrogate continuity<br>IF a VE is admitted to the hospital or nursing home, THEN within 48 hours of admission, the medical record should contain the patient's surrogate decision maker or documentation of a discussion to identify or search for surrogate decision maker, BECAUSE specification of a surrogate decision maker facilitates decision making for patients at risk of losing decision making capacity.<br>Process | **Numerator**: -<br>**Denominator**: -<br>**Exclusion**: -<br>**Performance standard**: - |
| 304 | Lorenz, 2007 | Care-preference documentation<br>IF a VE with severe dementia is admitted to the hospital and survives 48 hours, THEN within 48 hours of admission, the medical record should document that the patient's preferences for care have been considered or an attempt was made to identify them, BECAUSE patient's values and preferences should guide life-sustaining care.<br>Process | **Numerator**: -<br>**Denominator**: -<br>**Exclusion**: -<br>**Performance standard**: - |

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| 305 | Lorenz, 2007 | Care-preference documentation<br>IF a VE is admitted to the ICU and survives 48 hours, THEN within 48 hours of ICU admission, the medical record should document that the patient's preferences for care have been considered or an attempt was made to identify them, BECAUSE patient's values and preferences should guide life-sustaining care.<br>Process | **Numerator**: -<br>**Denominator**: -<br>**Exclusion**: -<br>**Performance standard**: - |
| 306 | Lorenz, 2007 | Decisions about life-sustaining treatment<br>IF a VE with decision-making capacity has orders in the hospital or nursing home to withhold or withdraw a life-sustaining treatment (e.g., DNR order), THEN the medical record should document patient participation in the decision or why the patient did not participate, BECAUSE the values of patients with decision-making capacity who wish to participate should guide important care decisions.<br>Process | **Numerator**: -<br>**Denominator**: -<br>**Exclusion**: -<br>**Performance standard**: - |
| 307 | Lorenz, 2007 | Mechanical ventilation preference<br>IF a hospitalized VE requires mechanical ventilation for longer than 48 hours, THEN within 48 hours of the initiation of the mechanical, the medical record should document the goals of care and the patient's preference for mechanical ventilation or why this information is unavailable, BECAUSE mechanical ventilation should be performed only when it is consistent with a patient's goals, and early | **Numerator**: -<br>**Denominator**: -<br>**Exclusion**: -<br>**Performance standard**: - |

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| | | consideration of prognosis and preferences will guide care to be consistent with the patient's values.<br>Process | |
| 308 | Lorenz, 2007 | Goals of care surrogate discussion<br>IF a VE dies an expected death with metastatic cancer, oxygen-dependent pulmonary disease, New York Heart Association (NYHA) Class III to IV congestive heart failure (CHF). end-stage (stage IV) renal disease, or dementia, THEN the chart should document discussion of the medical condition and goals for treatment with a designated surrogate, the patient's preferences for not involving a designated surrogate in discussions, or a note that a surrogate decision maker is unavailable within 6 months before death, BECAUSE temporary decisional incapacity is common in these health states, and therefore, surrogates are at risk of being called upon to assist in achieving patient preferences, yet it is not routine for physicians to involve surrogates in care planning.<br>Process | **Numerator**: -<br>**Denominator**: -<br>**Exclusion**: -<br>**Performance standard**: - |
| 309 | Lorenz, 2007 | Gastrostomy tube placement<br>IF a VE with dementia has a gastrostomy or jejunum tube placed, THEN before placement, the medical record should document patient preferences concerning tube feeding; discussion of patient preferences or best interests if the patient is decisionally incapacitated and a surrogate decision maker is available; or use of | **Numerator**: -<br>**Denominator**: -<br>**Exclusion**: -<br>**Performance standard**: - |

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| | | a formal decision mechanism is the patient is decisionally incapacitated and a surrogate decision maker is not available, BECAUSE many patients would not want to receive tube feeding to maintain survival is a persistent severely compromised health state, and decisions are often made to place gastrostomy tubes when patients can no longer participate in decisions.<br>Process | |
| 310 | Saliba, 2004 | ALL residents, within 2 weeks of NH admission, should have physician notes or orders documenting a discussion or decision concerning all of the following: resuscitation status, hospital transfers, and advance directives, unless there is documentation that the resident is not capable of understanding and surrogate could not be located. This information should remain available in the chart throughout the resident's stay.<br>Process | **Numerator**: -<br>**Denominator**: -<br>**Exclusion**: When there is documentation that the resident is not capable of understanding and surrogate could not be located<br>**Performance standard**: 100% |
| 311 | NEW Miyashita, 2008 | Decision making and preference of care: Patient's preference of care or advance directives.<br>Outcome | **Numerator:** Number of patients for whom this indicator was documented on admission or within the last 2 weeks of the hospitalization<br>**Denominator:** All patients who died (retrospectively identified)<br>**Exclusion: -**<br>**Performance standard: -** |
| 312 | NEW Sato, 2008 | Decision making and preference of care: Discussion with patient about goals of care.<br>Process | **Numerator:** Number of patients for whom this indicator was documented on admission or within the last 2 weeks of the hospitalization<br>**Denominator:** All patients who died (retrospectively identified)<br>**Exclusion: -**<br>**Performance standard: -** |
| 313 | NEW Sato, 2008 | Decision making and preference of care: Discussion with patient about do-not-resuscitate order.<br>Process | **Numerator:** Number of patients for whom this indicator was documented on admission or within the last 2 weeks of the hospitalization<br>**Denominator:** All patients who died (retrospectively identified)<br>**Exclusion: -**<br>**Performance standard: -** |

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| 314 | $^{\text{NEW}}$ Miyashita, 2008<br>Sato, 2008 | Family care: Discussion with family about do-not-resuscitate order.<br>Process | **Numerator:** Number of patients for whom this indicator was documented on admission or within the last 2 weeks of the hospitalization<br>**Denominator:** All patients who died (retrospectively identified)<br>**Exclusion: -** |
| 315 | $^{\text{NEW}}$ Miyashita, 2008, omitted in Sato, 2008 | Psychosocial and spiritual concerns: Patient's preference for bowel and bladder excretion.<br>Outcome | **Numerator:** Number of patients for whom this indicator was documented on admission or within the last 2 weeks of the hospitalization<br>**Denominator:** All patients who died (retrospectively identified)<br>**Exclusion: -**<br>**Performance standard: -** |
| 316 | $^{\text{NEW}}$ Schenck, 2010 | Ethical and legal aspects of care: Percent of patients with chart documentation of preferences for life sustaining treatments.<br>Outcome | **Numerator:** Number of patients with documentation = "Y"<br>**Denominator:** Number of Patients<br>**Exclusion: -**<br>**Performance standard: -** |
| 317 | $^{\text{NEW}}$ Schenck, 2010 | Ethical and legal aspects of care: Percent of patients with chart documentation of an advanced directive (living will or health care power of attorney) or discussion that there is no advanced directive.<br>Outcome | **Numerator:** Number of patients with documentation of advanced directive="Y" or Discussion of no advanced directive = "Y"<br>**Denominator:** Number of Patients<br>**Exclusion: -**<br>**Performance standard: -** |
| 318 | $^{\text{NEW}}$ Schenck, 2010 | Adverse Events: Selected number of occurrences per 100 patient days (falls, medication errors, DME concerns, and patient or family complaints).<br>Process | **Numerator:** The total number of occurrences reported in the time period<br>**Denominator:** Total number of patient days in the time period<br>**Exclusion: -**<br>**Performance standard: -** |
| 319 | $^{\text{NEW}}$ Quality Markers, 2009 | QM for acute hospitals: They offer care plans to all patients who are approaching the end of life.<br>Outcome | Proportion of all deceased patients who had an end of life care plan (or documentation that a care plan had been offered but declined)<br>**Numerator**: -<br>**Denominator**: -<br>**Exclusion**: -<br>**Performance standard**: - |
| 320 | $^{\text{NEW}}$ Quality Markers, 2009 | QM for community hospitals: They offer care plans to all patients who are approaching the end of life.<br>Outcome | Proportion of all deceased patients who had an end of life care plan (or documentation that a care plan had been offered but declined)<br>**Numerator**: -<br>**Denominator**: -<br>**Exclusion**: -<br>**Performance standard**: - |

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| 321 | NEW Lorenz, 2009 | Information and care planning<br>IF a patient with advanced cancer dies an expected death, THEN there should be documentation of an advance directive or a surrogate decision maker in the medical record.<br>Process | **Numerator**: -<br>**Denominator**: -<br>**Exclusion**: -<br>**Performance standard**: - |
| 322 | NEW Lorenz, 2009 | Information and care planning<br>IF a patient with advanced cancer is admitted to the ICU and survives 48 hours, THEN within 48 hours of ICU admission, the medical record should document the patient's preferences for care or attempt to identify them.<br>Process | **Numerator**: -<br>**Denominator**: -<br>**Exclusion**: -<br>**Performance standard**: - |
| 323 | NEW Lorenz, 2009 | Information and care planning IF a patient with advanced cancer is mechanically ventilated in the ICU, THEN within 48 hours of admission to the ICU, the medical record should document the patient's preference for mechanical ventilation or why this information is unavailable.<br>Process | **Numerator**: -<br>**Denominator**: -<br>**Exclusion**: -<br>**Performance standard**: - |
| 324 | NEW Claessen, 2011 | Generic aspects: Presence of documentation concerning the desired care and treatment at the end of life<br>The patient's wishes with regard to care and treatment at the end of life must be documented.<br>Process | **Numerator**: The number of patients for whom the desired care and treatment at the end of life is documented<br>**Denominator**: Total number of patient files consulted<br>**Exclusion**: -<br>**Performance standard**: - |
| **30** | NEW ELCQuA, 2011<br>This indicator suits domain 1 and 8. | People approaching the end of life are identified.<br>Process | **Numerator:** Number of deaths on register OR with identified advance care plan<br>**Denominator:** Total deaths for same catchment and time period<br>**Performance standard: -**<br>**Numerator:** Non-cancer deaths on register OR with an advance care plan identified<br>**Denominator:** Non-cancer deaths for same catchment for same time period<br>**Performance standard: -** |

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| 325 | NEW ELCQuA, 2011 | Individuals have an agreed care plan.<br>Process | **Numerator:** Number of deceased patients with care plan in place<br>**Denominator:** Total deaths for same time period<br>**Exclusion:** -<br>**Performance standard:** Care plans in place for all patients approaching the end of life |
| **284** | NEW ELCQuA, 2011<br>This indicator suits domain 7 and 8. | Individuals are offered an advance care plan.<br>Process/Outcome | **Numerator:** Number of patients who died who were registered to have an advance care plan in place plus number offered a care plan but without a plan in place<br>**Denominator:** Total deaths<br>**Exclusion:** -<br>**Performance standard:** All patients/service users requiring end of life care or approaching end of life are offered advance care planning conversations<br>**Numerator:** Number dying in preferred place of death.<br>**Denominator:** Total number dying with an advance care plan in place<br>**Exclusion**: -<br>**Performance standard**: -<br>**Numerator:** Number of patients who died in their own home or care home<br>**Denominator:** Total deaths for same time period<br>**Exclusion**: -<br>**Performance standard**: -<br>**Numerator:** Number of deaths in hospital within 3 days of admission by PCT or acute site.<br>**Denominator:** Total deaths in same catchment for same time period<br>**Exclusion**: -<br>**Performance standard**: - |
| 326 | NEW ELCQuA, 2011 | Patients with an agreed Do Not Attempt Resuscitation policy in place have their preferences respected.<br>Process | **Numerator:** Number of patients with a DNAR in place where resuscitation is attempted<br>**Denominator:** Total number of deaths where a DNAR is in place<br>**Exclusion**: -<br>**Performance standard**: - |

NEW These quality indicators have been found in this update.

Note: Quality Indicators that suit multiple NCP-categories are indicated with a bold number, and keep the same quality indicator number as they had in the first category they suited.

# REFERENCES APPENDIX 3

## Earle, 2006

- National Quality Forum. National voluntary consensus standards for symptom management and end-of-life care in cancer patients. 2006. Available from http://www.qualityforum.org/. Accessed 19th December 2014.
- Earle CC, Park ER, Lai B, Weeks JC, Ayanian JZ, Block S. Identifying potential indicators of the quality of end-of-life cancer care from administrative data. J Clin Oncol 2003;21(6):1133-1138.
- Earle CC, Neville BA, Landrum MB, Souza JM, Weeks JC, Block SD, Grunfeld E, Ayanian JZ. Evaluating claims-based indicators of the intensity of end-of-life cancer care. Int J Qual Health Care 2005;17(6):505-509.

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

One of the references by Grunfeld et al. (2006) found by Pasman et al. seems to regard a new set of indicators, and is in this update considered as describing a new set of indicators, together with a newly retrieved reference.

## Grunfeld, 2008

- Grunfeld E, Lethbridge L, Dewar R, Lawson B, Paszat LF, Johnston G, Burge F, McIntyre P, Earle CC. 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.
- Grunfeld E, Urquhart R, Mykhalovskiy E, Folkes A, Johnston G, Burge FI, Earle CC, Dent S. Toward population-based indicators of quality end-of-life care: testing stakeholder agreement. Cancer 2008;112(10):2301-2308.

Subject quality indicator set: Palliative cancer care

## Yabroff, 2004

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

Subject quality indicator set: Palliative cancer care

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

## Lorenz, 2009

- Lorenz KA, Dy SM, Naeim A, Walling AM, Sanati H, Smith P, Shanman R, Roth CP, Asch SM. Quality measures for supportive cancer care: the Cancer Quality-ASSIST Project. J Pain Symptom Manage 2009;37(6):943-964.
- Dy SM, Lorenz KA, O'Neill SM, Asch SM, Walling AM, Tisnado D, Antonio AL, Malin JL. Cancer Quality-ASSIST supportive oncology quality indicator set: feasibility, reliability, and validity testing. Cancer 2010;116(13):3267-3275.

Subject quality indicator set: Palliative cancer care

## Miyashita, 2008

- Miyashita M, Nakamura A, Morita T, Bito S. Identification of quality indicators of end-of-life cancer care from medical chart review using a modified Delphi method in Japan. American Journal of Hospice & Palliative Medicine 2008;25(1):33-38.
- Sato K, Miyashita M, Morita T, Sanjo M, Shima Y, Uchitomi Y. 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 Pall Med 2008;11:729-737.

Subject quality indicator set: Palliative cancer care

## Peruselli, 1997

- Peruselli C, Marinari M, Brivio B, Castagnini G, Cavana M, Centrone G, Magni C, Merlini M, Scaccabaro GL, Paci E. Evaluating a home palliative care service: development of indicators for a continuous quality improvement program. J Palliat Care. 1997 Autumn;13(3):34-42.

Subject quality indicator set: Home palliative care

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

## Keay, 1994

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

Subject quality indicator set: Palliative nursing home care

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

## Lorenz, 2007; Saliba, 2004

- Wenger NS, Rosenfeld K. Quality indicators for end-of-life care in vulnerable elders. Ann Intern Med. 2001 Oct 16;135(8 Pt 2):677-852
- Saliba D, Solomon D, Rubenstein L, Young R, Schnelle J, Roth C, Wenger N. Feasibility of quality indicators for the management of geriatric syndromes in nursing home residents. J Am Med Dir Assoc. 2004 Sep-Oct;5(5):310-319
- Lorenz KA, Rosenfeld K, Wenger N. Quality indicators for palliative and end-of-life care in vulnerable elders. J Am Geriatr Soc. 2007 Oct;55 Suppl 2:S318-326.
- Anonymous. Assessing care of vulnerable elders-3 quality indicators. J Am Geriatr Soc 2007 Oct;55 Suppl 2:S464-S487.

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

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

## van der Ploeg, 2008

- van der Ploeg E, Depla MF, Shekelle P, Rigter H, Mackenbach JP. Developing quality indicators for general practice care for vulnerable elders; transfer from US to The Netherlands. Qual Saf Health Care. 2008 Aug;17(4):291-295.

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

Shortened and adapted version of the ACOVE end-of-life care subset. Overlapping quality indicators are only mentioned once.

## National Hospice and Palliative Care Organization (NHPCO), 2006

- National Quality Forum. National voluntary consensus standards for symptom management and end-of-life care in cancer patients. 2006. Available from http://www.qualityforum.org/. Accessed 19th December 2014.

Subject quality indicator set: Family evaluation of hospice care

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

## Schenck, 2010

- Schenck AP, Rokoske FS, Durham DD, Cagle JG, Hanson LC. The PEACE Project: identification of quality measures for hospice and palliative care. J Palliat Med 2010;13(12):1451-1459.

Subject quality indicator set: Hospice or palliative care

## Mularski, 2006; Nelson, 2006

- Mularski RA, Curtis JR, Billings JA, Burt R, Byock I, Fuhrman C, Mosenthal AC, Medina J, Ray DE, Rubenfeld GD, Schneiderman LJ, Treece PD, Truog RD, Levy MM. Proposed quality measures for palliative care in the critically ill: a consensus from the Robert Wood Johnson Foundation Critical Care Workgroup. Crit Care Med 2006;34(11 Suppl):S404-S411.
- Nelson JE, Mulkerin CM, Adams LL, Pronovost PJ. Improving comfort and communication in the ICU: a practical new tool for palliative care performance measurement and feedback. Qual Saf Health Care 2006;15(4):264-271.
- Clarke EB, Curtis JR, Luce JM, Levy M, Danis M, Nelson J, Solomon MZ. Quality indicators for end-of-life care in the intensive care unit. Crit Care Med 2003;31(9):2255-2262.

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

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

## Twaddle, 2007

- Twaddle ML, Maxwell TL, Cassel JB, Liao S, Coyne PJ, Usher BM, Amin A, Cuny J. Palliative care benchmarks from academic medical centers. J Palliat Med 2007;10(1):86-98.

Subject quality indicator set: Hospital-based palliative care

## Claessen, 2011

- Claessen SJJ, Francke AL, Belarbi HE, Pasman HR, van der Putten MJA, Deliens L. 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.
- Brandt HE, Francke AL, Pasman HRW, Claessen SJJ, van der Putten MJA, Deliens L. Indicatoren voor Palliatieve Zorg: Ontwikkeling en toetsing van een set kwaliteitsindicatoren voor de palliatieve zorgverlening. [Quality indicators for palliative care: development and testing of a set of quality indicators for palliative care]. [In Dutch]. Utrecht: NIVEL, 2009. Available at http://www.nivel.nl/sites/default/files/bestanden/rapport-indicatoren-palliatieve-zorg.pdf. Accessed 19th December 2014.

Subject quality indicator set: Palliative care for adult patients in all settings where palliative care is provided

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

## Eagar, 2010

- Eagar K, Watters P, Currow DC, Aoun SM, Yates P. 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.
- Palliative Care Outcomes Collaboration (PCOC). National Benchmarks and Targets. 2009. Available from https://ahsri.uow.edu.au/pcoc/benchmarkmeasures/index.html. Accessed 19th December 2014.

Subject quality indicator set: Specialist palliative care settings

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

## Quality Markers, 2009

- Department of Health. End of Life Care Strategy: Quality Markers and measures for end of life care. Available from http://webarchive.nationalarchives.gov.uk/20130107105354/http://www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsPolicyAndGuidance/DH_101681. Accessed 19th December 2014.

Subject quality indicator set: Several settings where palliative care is provided

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

## ELCQuA, 2011

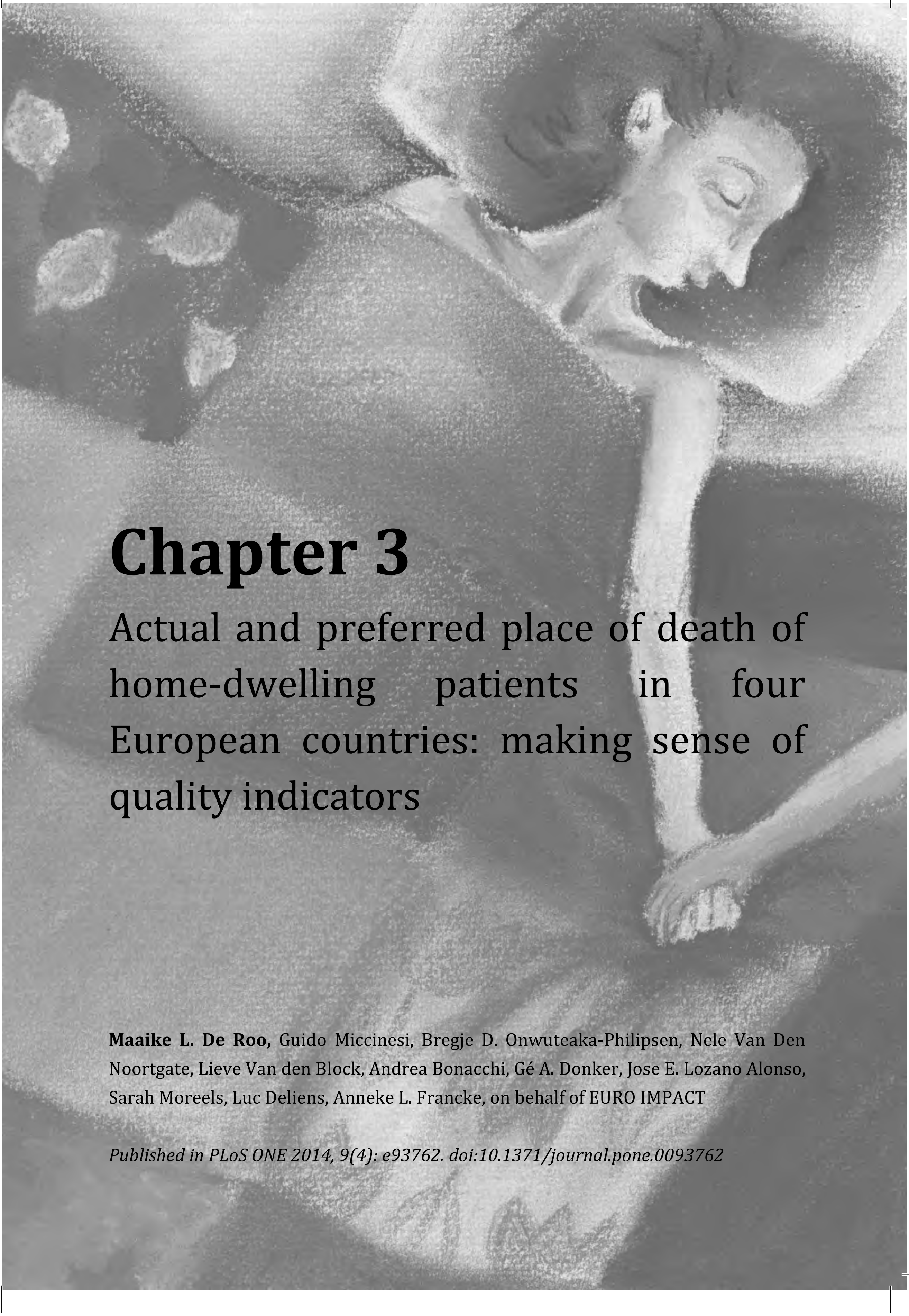
- National Health Service. End of Life Care Quality Assessment (ELCQuA). 2011. Available from http://www.elcqua.nhs.uk/. Accessed 19th December 2014.

Subject quality indicator set: Several settings where palliative care is provided

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

# PART 2

## The Use of Quality Indicators in Cross-country Comparisons



# Chapter 3

## Actual and preferred place of death of home-dwelling patients in four European countries: making sense of quality indicators

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## ABSTRACT

**BACKGROUND –** Dying at home and dying at the preferred place of death are advocated to be desirable outcomes of palliative care. More insight is needed in their usefulness as quality indicators. Our objective is to describe whether “the percentage of patients dying at home” and “the percentage of patients who died in their place of preference” are feasible and informative quality indicators.

**METHODS AND FINDINGS –** A mortality follow-back study was conducted, based on data recorded by representative GP networks regarding home-dwelling patients who died non-suddenly in Belgium (n=1036), the Netherlands (n=512), Italy (n=1639) or Spain (n=565). “The percentage of patients dying at home” ranged between 35.3% (Belgium) and 50.6% (the Netherlands) in the four countries, while “the percentage of patients dying at their preferred place of death” ranged between 67.8% (Italy) and 86.0% (Spain). Both indicators were strongly associated with palliative care provision by the GP (odds ratios of 1.55-13.23 and 2.30-6.63 respectively). The quality indicator concerning the preferred place of death offers a broader view than the indicator concerning home deaths, as it takes into account all preferences met in all locations. However, GPs did not know the preferences for place of death in 39.6% (the Netherlands) to 70.3% (Italy), whereas the actual place of death was known in almost all cases.

**CONCLUSION –** GPs know their patients’ actual place of death, making the percentage of home deaths a feasible indicator for collection by GPs. However, patients' preferred place of death was often unknown to the GP. We therefore recommend using information from relatives as long as information from GPs on the preferred place of death is lacking. Timely communication about the place where patients want to be cared for at the end of life remains a challenge for GPs.

## INTRODUCTION

The majority of people, both the general public and terminally ill patients, prefer to die at home.[1-4] Therefore, the place where people die has received a great deal of interest in the last few decades and is now an extensively studied subject worldwide.[5-11] The proportion of people dying at home ranges from 12% to 60%.[4,6-10,12-14] Traditionally, palliative care professionals have tried to ensure that people are cared for at home until the end of life,[15-17] considering dying at home as more natural.[18] Home deaths may be considered as an outcome of high quality palliative care. The view of the home as the optimal place to die has been challenged, with the establishment of palliative care in hospitals, nursing homes, hospices and other in-patient facilities.[17,19] Interpreting the proportion of home deaths as an indicator of high-quality palliative care implies that people who were not able to die at home only received second-best care.[20-22] Not being able to die at home could therefore be seen as a failure in the care given to these patients, even if the patient was actually admitted to e.g. a hospital or hospice for perfectly valid reasons and in accordance with the patient's wishes.[15,20]

Looking at whether patients die at their preferred place may therefore do more justice to the diversity of characteristics and preferences of patients. Some authors have therefore stated that ensuring death occurs in the preferred place is a more appropriate reflection of the quality than the proportion of home deaths.[2,10,23-25] Their main criticisms of home deaths as a quality indicator are that this implies a home death is optimal for the patients whereas it is not always realistic,[5,8,10,15,17,22,26-29] due to the high burden on informal caregivers, the inadequate quality and quantity of resources in the home situation and the unrelieved suffering. On top of that and partly for the same reasons, a minority of patients do prefer other care locations in contrast to the majority of patients who prefer to die at home.[3,26,30-33] Therefore, whether patients die at their preferred place has only recently started to receive attention.[1,31,32,34,35] Studies show that people die at the preferred place of death in 29% to 94% of cases.[1,2,26]

The actual place where people die and whether people die at their preferred place are often mentioned in studies aiming at improving care at the end of life, suggesting that they could function as indicators of the quality of palliative care.[1,24,36-40] Quality indicators are explicitly defined, measurable items referring to the outcomes, processes or structure of care.[41,42] A recent systematic review[43] revealed over 300 quality indicators developed for palliative care; this included indicators focusing on the place of death and preferred place of death, but to our knowledge their actual function as indicators of the quality of care has never been studied in detail.[15] Considering the growing attention paid to quality indicators in recent years,[43,44] studying the actual place of death and preferred place of death from a quality indicator perspective could provide useful new insights.

In this paper, we want to ascertain whether the quality indicators "the percentage of patients dying at home" and "the percentage of patients who died in their place of preference" are feasible and informative quality indicators. This paper aims to answer the following research questions in a population of patients who died non-suddenly and who were living at home in the last month of life in Belgium, the Netherlands, Italy and Spain:

- What are the scores of the two quality indicators for home-dwelling patients with a non-sudden death in Belgium, the Netherlands, Italy and Spain?
- Are these quality indicators feasible in terms of the number of missing values when derived from the data of representative general practitioner (GP) networks?
- Are quality differences between countries revealed in these indicator scores? What kind of information do the two quality indicators give us in terms of measured quality? Do they overlap, or should they be used in combination?
- Are the expected differences in quality indicator scores between countries related to differences in care characteristics (adjusting for differences in patient characteristics)? If so, this means that influencing these care characteristics may lead to more patient-centred care, reflected in higher indicator scores, meaning more people would die at home and/or at their preferred place.

## METHODS

### Study design

Data came from the European Sentinel GP Networks Monitoring End-of-Life Care (EURO SENTI-MELC) study, a mortality follow-back study on monitoring end-of-life care in four European countries, namely Belgium, the Netherlands, Spain and Italy. For this study, we used data from the nationally representative GP networks collected in 2009 (all countries except Spain), 2010 (all four countries) and 2011 (Spain only). The

GP sentinel networks cover 1.8% and 0.8% of the Belgian and Dutch national populations respectively.[45-47] The Spanish sentinel network represents 3.5% of the patient population in the Castilla and León region (in the northwest) and 2.2% in the Valencia region (in the east).[47,48] The Italian data came from a new GP network set up for this study[49] and were collected from nine of the 146 health districts, covering about 4% of the patient population.[47]

### Study population

The recorded data were analysed of deceased adult patients (aged 18 and above), who were part of a GP's practice and had died non-suddenly according to their GP. Since this study examines the care delivered at the end of life, the data of people who died suddenly and unexpectedly according to their GP were excluded, leaving a population that was eligible for palliative care.[45] Furthermore, the data of deceased people who had been living in long-term care facilities (nursing homes, residential homes or care homes) for more than 15 days in the last month of life were excluded in all four countries. This choice was made since we were primarily interested in the place of death and preferred place of death of people mainly living at home, and also to enhance comparability of the datasets of the four countries involved since the Dutch SENTI-MELC data set did not include nursing-home residents (in Dutch nursing homes, elderly-care physicians have the medical responsibility rather than GPs).[50] (Figure 1 shows a flowchart of the selected sample.)

### Selected quality indicators

For the selection of the quality indicators, we used a list of 326 quality indicators for palliative care found in a recent systematic review.[43] Four of these 326 indicators were related to the actual place of death and eight indicators concerned dying at the preferred place of care. From these twelve indicators, we selected two indicators that we could calculate with the existing EURO SENTI-MELC dataset. The first quality indicator selected, "the percentage of patients dying at home", comes from a set of quality indicators developed in Italy for palliative home care.[40]

The indicator is calculated using "the number of patients dying at home" as the numerator and "the total number of patients" as the denominator. The performance standard specified by the developers is that at least 95% of the patients receiving home palliative care should die at home. The second quality indicator selected concerns "the percentage of patients who died in the location of their preference". This quality indicator was found in two indicator sets that were developed for a wider range of settings.[24,38] In one of the sets[38] the indicator was calculated using "the number of relatives who indicate that the patient died in the location of his/her preference" as the numerator and "the total number of relatives for whom this quality indicator was measured" as the denominator. We used the GP's knowledge of the patient's preferred place of death to calculate this indicator.

## Data collection

The data needed for the calculation of these two quality indicators were taken from the data of the EURO SENTI-MELC study in which GPs recorded the characteristics of recently deceased patients on weekly basis using a standardised questionnaire. Recall bias was minimised by requiring registration to be no more than one week after the GP had been informed of the patient's death.[47] In the questionnaire, GPs were asked about the actual place of death [at home or living with family, in a care home (Belgium and Italy)/elderly home (the Netherlands and Spain), in hospital, in a palliative care unit/hospice, or elsewhere (namely); dichotomised into "at home" (i.e. at home or living with family) vs. "not at home"].

In addition, the patient's preference regarding place of death was asked in the question "Were you informed (verbally or in writing) of the patient's preference regarding place of death?". If the answer to this question was "yes", the GP was then asked "Where did this patient prefer to die?" and could choose from these options: at home or living with family, in a care home (Belgium and Italy)/elderly home (Netherlands and Spain), in hospital, in a palliative care unit/hospice or elsewhere (namely). The questionnaire also included the following questions:

- The provision of palliative care by the GP, as judged by the GPs themselves [no; yes, but not until death; yes, until death; dichotomized into "yes" and "no"];
- The importance of care goals in the second to fourth week before the patient died, as judged by the GPs themselves: treatment aimed at cure, treatment aimed at prolonging life and treatment aimed at palliation, rated on a five-point Likert scale (1 "not at all important" to 5 "very important"). These scores were dichotomized into the categories "important to very important" (scores of 4 and 5) and "not so important" (scores of less than 4).

## Informed consent and patient anonymity

After being informed of the objectives and procedures of the study, participating GPs gave written informed consent at the beginning of each registration year. Strict procedures regarding patient anonymity were employed during data collection and entry; every patient received an anonymous reference code from their GP and any identifying patient and GP data (such as date of birth, postcode and GP identification number) were replaced with aggregate categories or anonymous codes.

### Ethical approval

The protocol of this study was approved by the Ethical Review Board of Brussels University Hospital of the Vrije Universiteit Brussel (2004), Belgium, and the Local Ethical Committee, “Comitato Etico della Azienda U.S.L. n. 9 di Grosseto” (2008), Tuscany, Italy. In the Netherlands and Spain, no ethical approval is required for the posthumous collection of anonymous patient data.

### Statistical analysis

We calculated the quality indicator “the percentage of patients dying at home” from the question concerning the place of death. The quality indicator “the percentage of patients who died in the place of their preference” was calculated based on the combined information concerning actual and preferred place of death. Descriptive statistics were used to describe the study population and the quality indicator scores.

To enable a valid comparison between countries in quality indicator scores, the quality indicator scores were standardised for patients’ gender, age at death, cause of death and diagnosis of dementia, using the distribution observed in the study population as a whole as the reference distribution.

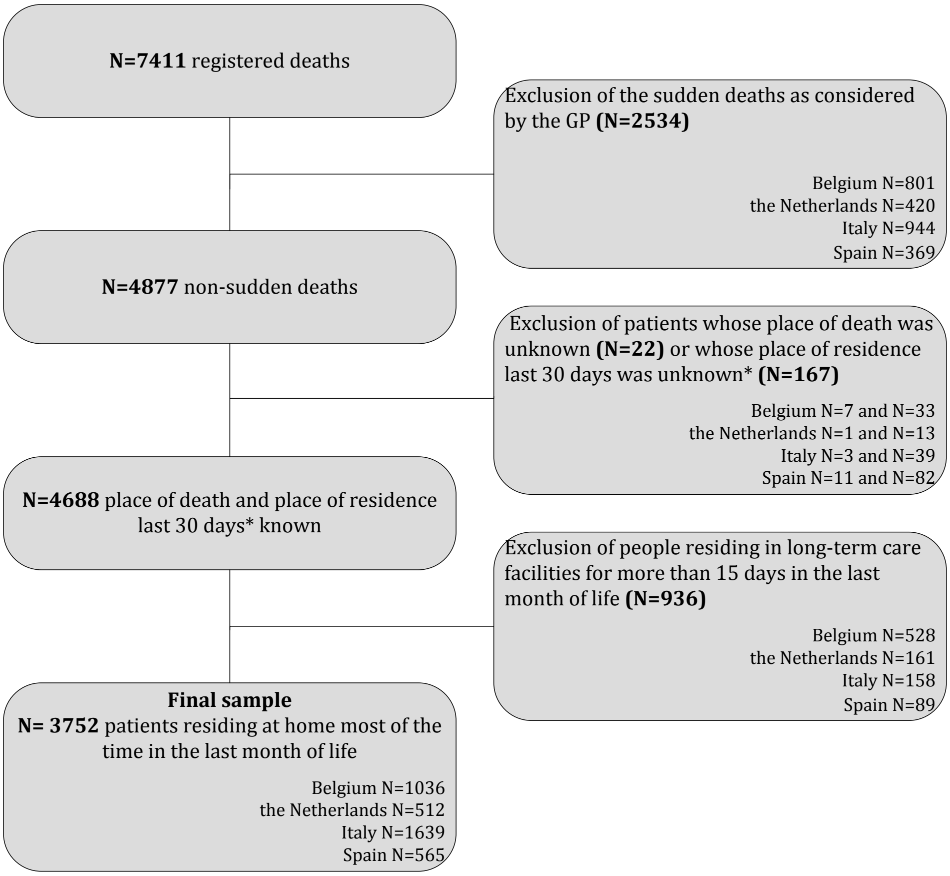
Multivariable logistic regression analyses were performed to identify the care characteristics associated with dying at home and dying at the place of preference adjusting for patient characteristics. The patient characteristics used for adjustment were gender [“male” vs. “female”], age at death [“18-64”, “65-84” or “85 and older”], cause of death [“cancer” vs. “non-cancer”] and diagnosis of dementia [“no”, “yes, mild dementia” and “yes, severe dementia”]. The care characteristics analysed were “GP provided palliative care” [“yes” vs. “no”] and care goals in the last 2-4 weeks of life of “treatment aimed at cure”, “treatment aimed at prolonging life” and “treatment aimed at comfort/palliation” [“important to very important” vs. “not so important”]. We performed a separate analysis per country, using a single multivariable model for each country, including the confounders (age, gender, cause of death, diagnosis of dementia) and the predictors (“GP provided palliative care” and the three care goals). We retained the confounders in the model regardless of their statistical significance. The analyses were performed using IBM SPSS Statistics software, Version 20.0 (IBM Corp., 2011, Armonk, NY), with a significance level $\alpha < 0.05$.

## RESULTS

### Description of the sample

Of the original 7411 registered deaths, GPs considered 4877 deaths as non-sudden. Exclusion of long-term care facility residents in all four countries left a total number of 3752 deaths: 1036 for Belgium, 512 for the Netherlands, 1639 for Italy and 565 for Spain (see Figure 1).

**Figure 1 – Flowchart of the sample selection**



* We excluded patients if place of residence was known for ≤ 15 days in the last month of life OR if place of residence was known for <30 days and a transition took place during this period.

In all countries except for Italy, the majority of the patients in the samples were male (Table 1). About one quarter of the Belgian and Dutch samples were aged 85 or older, whereas this group of the very elderly comprised around 40% in Italy and Spain. Malignancy was the main cause of death in all countries, but the proportion in the Netherlands was higher (60.8% versus 40.8-48.4%). Fewer patients were diagnosed with dementia in the Netherlands than in the other three countries (7.3% versus 17.4-27.7%). In all countries except for Belgium, the majority of patients received palliative care from their GP (Table 1). Palliation was considered an important care goal in the last 2-4 weeks of life for the majority of the patients in all countries. Cure was still an important care goal in 14.2-24.0% of patients and prolonging life in 21.5-39.3% (Table 1).

### Quality indicator scores per country

Belgium had the lowest scores on the standardised quality indicator “the percentage of patients dying at home”: in Belgium, only 35.3% of the sample of GPs’ patients living at home and with a non-sudden death died at home. Home deaths accounted for 49.1-50.6% in the samples in the other three countries (see Table 2).

Italy had the lowest scores for the standardised quality indicator “the percentage of patients who died at their preferred place of death”: in Italy, 67.8% of the GPs’ patients who lived at home and died non-suddenly died at the preferred place, while this percentage was highest in Spain (86.0%) (Table 2). These quality indicator scores standardised for gender, age, cause of death and diagnosis of dementia, differed slightly from the crude, observed percentages, by 0.3% to 7.8% (see Table 2).

## Table 1 – Characteristics of the patients and of the care provided per country

| | BELGIUM (N=1036) N (%) | NETHERLANDS (N=512) N (%) | ITALY (N=1639) N (%) | SPAIN (N=565) N (%) |
|---|---|---|---|---|
| **PATIENT CHARACTERISTICS** | | | | |
| **Gender**[*] | | | | |
| Female | 471 (45.6) | 235 (46.4) | 857 (52.3) | 249 (44.6) |
| Male | 563 (54.4) | 271 (53.6) | 782 (47.7) | 309 (55.4) |
| **Age at death**[†] | | | | |
| 18-64 | 199 (19.4) | 113 (22.1) | 217 (13.2) | 64 (11.3) |
| 65-84 | 559 (54.4) | 280 (54.7) | 779 (47.5) | 268 (47.4) |
| 85 and older | 269 (26.2) | 119 (23.2) | 643 (39.2) | 233 (41.2) |
| **Cause of death**[‡] | | | | |
| Cancer | 501 (48.4) | 310 (60.8) | 767 (47.9) | 226 (40.8) |
| Cardiovascular diseases (except stroke) | 135 (13.0) | 62 (12.2) | 327 (20.4) | 105 (19.0) |
| Respiratory diseases | 95 (9.2) | 42 (8.2) | 117 (7.3) | 59 (10.6) |
| Neurologic diseases | 47 (4.5) | 14 (2.7) | 89 (5.6) | 29 (5.2) |
| CVA - stroke | 57 (5.5) | 18 (3.5) | 149 (9.3) | 47 (8.5) |
| Other | 200 (19.3) | 64 (12.5) | 151 (9.4) | 88 (15.9) |
| **Diagnosed dementia**[§] | | | | |
| No | 844 (82.6) | 458 (92.7) | 1183 (73.1) | 401 (72.4) |
| Yes, mild dementia | 102 (10.0) | 22 (4.5) | 228 (14.1) | 79 (14.3) |
| Yes, severe dementia | 76 (7.4) | 14 (2.8) | 207 (12.8) | 74 (13.4) |
| **CARE CHARACTERISTICS** | | | | |
| **GP provided palliative care**[\|\|] | | | | |
| No | 573 (55.4) | 264 (39.7) | 725 (44.3) | 207 (38.8) |
| Yes | 462 (44.6) | 299 (60.3) | 910 (55.7) | 326 (61.2) |
| **Cure is a (very) important care goal in week 2-4 before death**[¶] | 227 (24.0) | 60 (14.2) | 230 (16.5) | 85 (19.5) |
| **Prolonging life is a (very) important care goal in week 2-4 before death**[**] | 304 (31.9) | 90 (21.5) | 558 (39.3) | 112 (26.7) |
| **Palliation is a (very) important care goal in week 2-4 before death**[††] | 647 (68.5) | 374 (87.8) | 781 (60.2) | 304 (67.1) |

* Missing values: Belgium N=2, the Netherlands N=6, Italy no missing values, Spain N=7.
† Missing values: Belgium N=9, the Netherlands, Italy and Spain no missing values.
‡ Missing values: Belgium N=1, the Netherlands N=2, Italy N=39, Spain N=11.
§ Missing values: Belgium N=14, the Netherlands N=18, Italy N=21, Spain N=11.
|| Missing values: Belgium N=1 , the Netherlands N=16 , Italy N=4 , Spain N=32.
¶ Missing values: Belgium N=90, the Netherlands N=88, Italy N=244, Spain N=132.
** Missing values: Belgium N=84, the Netherlands N=94, Italy N=219, Spain N=146.
†† Missing values: Belgium N=91, the Netherlands N=86, Italy N=342, Spain N=112.

**Table 2 – Observed and standardised quality indicator (QI) scores per country**

| Observed and standardised QI scores | BELGIUM (N=1036) | NETHERLANDS (N=512) | ITALY (N=1639) | SPAIN (N=565) |
|---|---|---|---|---|
| **% of patients dying at home** | 34.7% | 52.5% | 50.9% | 51.3% |
| **Standardised % of patients dying at home*** | 35.3% | 50.6% | 49.1% | 50.5% |
| N unanswered questions† | 7 | 1 | 3 | 11 |
| **% of patients who died in the location of their preference‡** | 72.3% | 83.2% | 69.7% | 87.9% |
| **Standardised % of patients who died in the location of their preference*** | 72.6% | 75.4% | 67.8% | 86.0% |
| N unanswered or inconsistently answered questions | 7 | 10 | 7 | 66 |
| N (%) preference unknown by GP | 592 (57.5%) | 199 (39.6%) | 1147 (70.3%) | 334 (66.9%) |

* These percentages have been standardised for gender, age, cause of death and diagnosis of dementia.
† These patients were excluded from our study (see Figure 1).
‡ This quality indicator was only calculated when preference was known: Belgium (n=437), the Netherlands (n=303), Italy (n=485) and Spain (n=165).

## Feasibility of collecting the necessary data for the quality indicators

The quality indicator concerning the actual place of death had very few missing values (Table 2). The number of cases where the questions were not answered or inconsistently answered was also low for the quality indicator concerning the preferred place of death (Table 2). On the other hand, high numbers of unknown preferences were seen for this indicator: from 39.6% in the Netherlands to 70.3% in Italy (Table 2). The proportion of cases where the preferences were unknown differed substantially between home deaths and deaths outside the home ($p<0.001$ in all four countries): the percentage of unknown preferences was higher for deaths outside the home, and this was the case for all four countries (Table 2).

## Comparison of the outcomes of the two quality indicators

A fair, simple comparison of the outcomes of two indicators is impossible, firstly due to the high percentage of missing information for the preferred place of death and secondly due to the fact that the proportion of missing values varies between countries and place of death (from 17.5% missing for patients in the Netherlands who died at home to 89.8% missing for patients in Spain who did not die at home, Table 3). For 71% of the patients in Belgium and 80% of the patients in the Netherlands who died at home, this was in accordance with their preferences known by the GP (Table 3). In Italy and Spain, these percentages were lower (38% and 47% respectively). Some people did not die at home but did die in the location of their preference, from 3% (Italy) to 15% (the Netherlands). The reverse (people who died at home when that was not the preferred place) occurred too.

**Table 3 – Comparison of the two quality indicators per country**

| | **BELGIUM (N=1036)** | | **NETHERLANDS (N=512)** | | **ITALY (N=1639)** | | **SPAIN (N=565)** | |
|---|---|---|---|---|---|---|---|---|
| | **At home N(%)*** | **Not at home N(%)†** | **At home N(%)*** | **Not at home N(%)†** | **At home N(%)*** | **Not at home N(%)†** | **At home N(%)*** | **Not at home N(%)†** |
| **Preference met** | 254 (70.6) | 62 (9.2) | 215 (79.9) | 37 (15.2) | 318 (38.1) | 20 (2.5) | 136 (46.9) | 9 (3.3) |
| **Preference not met** | 5 (1.4) | 116 (17.2) | 7 (2.6) | 44 (18.1) | 2 (0.2) | 145 (18.0) | 1 (0.3) | 19 (6.9) |
| **Preference unknown‡** | 101 (28.1) | 498 (73.7) | 47 (17.5) | 162 (66.7) | 515 (61.7) | 639 (79.5) | 153 (52.8) | 247 (89.8) |

* Percentages are the percentage of deaths at home.
† Percentages are the percentage of deaths not at home.
‡ Including unanswered and inconsistently answered questions.

### Care characteristics associated with quality indicators

Receiving palliative care from the GP is positively associated with dying at home (Table 4). This association is greatest in Belgium and the Netherlands (OR of 8.37 and 13.23 respectively). If cure is an important care goal in the last 2-4 weeks of life, people are less likely to die at home. This association is only significant in Belgium and Spain (OR of 0.57 and 0.48 respectively). If prolonging life is an important care goal in the last weeks of life, people are less likely to die at home. This association was only significant in Italy and Spain (OR 0.75 and 0.41 respectively). Palliation as an important care goal does not seem to have a consistent association with the place of death.

Dying at the place of preference is also positively associated with receiving palliative care from the GP in all countries, except for Spain (Table 4). The associations of other care characteristics with dying at the preferred place are not statistically significant.

## Table 4 – Associations of care characteristics with the two quality indicators per country

| | BELGIUM | | NETHERLANDS | | ITALY | | SPAIN | |
|---|---|---|---|---|---|---|---|---|
| | (N=1036) | (N=437) | (N=512) | (N=303) | (N=1639) | (N=485) | (N=565) | (N=165) |
| | **Home death OR (95% CI)** | **Preference met OR (95% CI)** | **Home death OR (95% CI)** | **Preference met OR (95% CI)** | **Home death OR (95% CI)** | **Preference met OR (95% CI)** | **Home death OR (95% CI)** | **Preference met OR (95% CI)** |
| **GP provided palliative care †** | | | | | | | | |
| Yes | **8.37 (5.7-12.2)**** | **4.14 (2.4-7.1)**** | **13.23 (7.2-24.4)**** | **6.63 (2.6-17.1)**** | **1.55 (1.2-2.0)*** | **2.30 (1.4-3.9)*** | **3.80 (2.3-6.3)**** | 3.87 (0.9-16.8) |
| **Care Goal rated as (very) important in week 2-4 before death ‡** | | | | | | | | |
| Cure | **0.57 (0.3-1.0)** | 0.80 (0.4-1.8) | 0.43 (0.2-1.2) | 1.42 (0.2-8.1) | 0.81 (0.6-1.2) | 0.88 (0.4-1.8) | **0.48 (0.2-0.9)** | 0.39 (0.1-2.3) |
| Prolonging life | 0.75 (0.5-1.1) | 0.78 (0.4-1.5) | 0.56 (0.3-1.1) | 0.52 (0.2-1.6) | **0.75 (0.6-1.0)** | 0.65 (0.4-1.8) | **0.41 (0.2-0.7)*** | 0.58 (0.1-3.3) |
| Palliation | 0.93 (0.6-1.4) | 0.94 (0.5-1.8) | 1.01 (0.4-2.4) | 0.89 (0.2-3.8) | 1.03 (0.8-1.3) | 1.25 (0.7-2.1) | 0.90 (0.5-1.5) | 0.32 (0.1-1.7) |

In this multivariable regression analyses, we corrected for gender, age at death, cause of death, diagnosis of dementia.
Odds ratios marked in bold are significant $p<0.05$.
Odds ratios marked in bold, with 1* are significant $p<0.01$.
Odds ratios marked in bold, with 2 ** are significant $p<0.001$.
† Reference category= no palliative care provided by the GP.
‡ Reference category= care goal considered as not so important.

## DISCUSSION

This is the first cross-national study to compare two quality indicators concerning the actual and preferred place of death for patients living at home who died non-suddenly. The percentage of home deaths varied between 35.3% (Belgium) and 50.6% (the Netherlands). Of patients whose preference for place of death was known, 67.8% (Italy) to 86.0% (Spain) died in the location of their preference. The quality indicator concerning the percentage of home deaths is easy to collect and measurement by GPs is feasible. However, the feasibility of the indicator concerning dying at the preferred place of death is hampered due to the high percentage of patients' preferences unknown by the GP (39.6% - 70.3%). Despite the high percentage of unknown preferences, the results indicate that there is a strong overlap between home deaths and deaths in the preferred location. Quality indicator scores are related to care characteristics: patients receiving palliative care from the GP were more likely to die at home and to die at the place of preference; and people were less likely to die at home if "cure" or "prolonging life" was an important care goal in the last 2-4 weeks of life.

Regarding the feasibility of collecting these data with the help of GPs, the quality indicator concerning home deaths had very few missing values, which shows that calculating this quality indicator with data gathered by GPs is feasible. The number of unanswered or inconsistently answered questions was also low for the quality indicator concerning the preferred place of death. However, high numbers of unknown preferences (39.7-69.8%) were seen for this indicator. Other studies have found unknown preference rates varying between 12% and 64%.[1,2,12,30,31,46,51] The proportion of unknown preferences was highest in the group of non-home deaths in all four countries, which is consistent with the findings of previous GP sentinel network studies.[30,52] Exploring patients' preferences may be a challenging process, because both the GP and the patient have to recognise the approaching end of life and have to be willing to talk about this subject.[20,21] In addition, some patients might not have a strong or pronounced preference and recording a definitive answer might be difficult. Patients also differ in the ability or willingness to express their preferences: culturally-related inhibitions preventing patients from talking openly about death or a low level of educational might hamper timely discussion.[2,20,27]

The indicator for the actual place of death has a defined performance standard of 95%, meaning that at least 95% of the patients receiving home palliative care should die at home.[40] One could argue that applying this performance standard to our data set is not realistic, since not all the patients in the data set received home palliative care, in contrast to the original indicator set. Alternatively, in the absence of a well-defined performance standard we can apply the "best-practice norm" principle: take a look at which country scores best and recommend this score as a target that other countries should aim for in future. In this study, one could therefore 51% as the minimum for the proportion of home deaths as a best-practice norm (the highest score, achieved in the Netherlands) and a minimum of 86% of patients dying at the preferred place if the preferred place was known by the GP (the highest score, achieved in Spain). This could be a way to overcome the absence of a performance standard, using a relative rather than an absolute norm as a threshold value for the quality of care.

We also saw that there is a strong overlap between dying at home and dying in the preferred location, found in all countries. Taking into account the unknown preferences, where we do not know if the preference was met, we can be sure that the majority of Belgian and Dutch patients (71% and 80% respectively) died at home according to their wishes, whereas this was only the case in a minority of Italian and Spanish patients (38% and 47% respectively). Of the people who did not die at home, 3% to 15% still died in their place of preference. These patients were not included in the "dying at home" quality indicator, suggesting that the indicator concerning preference covers a wider group of patients who died as preferred.

In addition, we revealed that some care characteristics were associated with the quality indicators, namely whether the GP provided palliative care and whether "cure" or "life prolongation" was an important treatment goal in the last two to four weeks of life. These effects are consistent with the existing literature: receiving chemotherapy in the last month of life has been associated with a reduced likelihood of a home death;[11] the provision of palliative care by the GP has been associated with an increased likelihood of home death;[5,19,30,53-57] dying in the preferred place of death has been associated with GP involvement and GP home visits.[32,35] The exact role of the GP in the provision of health care in general and more specifically in the provision of palliative care differs between countries. In the Netherlands, the GP has not only a high level of responsibility as a gatekeeper of referrals to hospital care and specialist care in general[47] but also plays the main role in the delivery of generalist palliative care at home.[58,59] GPs in Spain also fulfil a gatekeeper function,[47] but share the responsibility of the organisation for palliative care with home care teams.[60] Palliative care is also a shared responsibility of GPs and multidisciplinary palliative home care teams in Belgium[61] and Italy;[62,63] in these countries, GPs are not gatekeepers in general, but they do have a coordinating role in the healthcare system since most people have a GP who they consult regularly. Although the role of GPs in the four countries differs, having the GP provide palliative care was positively associated with dying at home and dying in the preferred place of death in all four countries. This suggests that improving these specific aspects, e.g. in this case improving the provision of palliative care by the GP and improving the GP-patient communication concerning preferences at the end of life (including the preferred place of death) can improve the quality of palliative care, which may then be reflected in higher quality indicator scores.

Although quality indicators are developed to provide an overview for a care setting or country as a whole, not for individual patients, we do think that it is important to keep the perspective of individual patients in mind when thinking about realistic performance standards for these indicators. Achieving a situation in which all patients die at home or all preferences are known might not be desirable or realistic. Home deaths may be suggested as an outcome of high-quality palliative care, but might give the impression that home deaths are the golden standard while for some patients this is not the best or preferred option. It misses out small minorities of patients who died in their preferred location elsewhere or who died at home without preferring home. Hence, it might seem that the percentage of patients dying at the preferred place of death is a better indicator, as it takes into account all preferences met in all locations. However our study showed that at present it is not feasible for GPs to collect data for the indicator on preferred place of death due to the high percentage of cases where the preferences are unknown to the GP. We therefore recommend that GPs actively improve their communication with patients so that they are able to find out and comply with patients' preferences. In cases where the GP is not aware of the patient's preference, we recommend measuring the indicator concerning the preferred place of death via relatives, as was originally intended in the original indicator set and was found to be feasible in a first test.[38] Another option is that, in the meantime, place of death could be used as a proxy, since there is a big overlap between the two indicators.

Furthermore, we should note that for care providers who aim to monitor and improve the quality of care provided, using only one quality indicator concerning the place of the death is not sufficient. Using a wider range of quality indicators, concerning different physical, psychological and spiritual aspects of palliative care, is necessary to provide a more complete picture of the quality of care provided.[21,43,64]

**Strengths and limitations**

This is the first cross-European study using existing data to compare the percentage of home deaths and the percentage of patients who died at their preferred place, and to assess their function as quality indicators for palliative care.

However, a limitation is that GPs themselves stated whether they had provided palliative care and we have no detailed information on what GPs considered as "providing palliative care". The reported preferences were also based on the GP's own observation and the high number of unknown preferences shows GPs did not know all the details of their patients' preferences. A possible bias can be that the sampled patients had more contact with their GPs and were thus able to state their preference more clearly to their GPs.

## CONCLUSION

The quality indicator "the percentage of home deaths" is easy for GPs to provide, but might give a narrow view of the quality of care, implying that home deaths are the golden standard. Hence it might seem that the quality indicator "dying at the preferred place" is a better alternative, as it takes into account all preferences met in all locations. However, it is not feasible at present to have this indicator measured by GPs due to the high percentage of cases where the preferences are unknown to the GP. We therefore suggest using information from relatives as long as information from GPs on the preferred place of death is lacking. Since dying at the preferred place of death offers great potential for becoming a good quality indicator for palliative care, we recommend that GPs pay ample attention to communication at the end of life, exploring patients' preferences, including the place of death.

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## REFERENCES

1. Bell CL, Somogyi-Zalud E, Masaki KH. Methodological review: measured and reported congruence between preferred and actual place of death. Palliat Med 2009;23(6):482-490.
2. Billingham MJ, Billingham SJ. Congruence between preferred and actual place of death according to the presence of malignant or non-malignant disease: a systematic review and meta-analysis. BMJ Supportive & Palliative Care 2013;3(2):144-154.
3. Gomes B, Calanzani N, Gysels M, Hall S, Higginson I. Heterogeneity and changes in preferences for dying at home: a systematic review. BMC Palliat Care 2013;12(1):7.
4. Gomes B, Higginson IJ, Calanzani N, Cohen J, Deliens L, Daveson BA, Bechinger-English D, Bausewein C, Ferreira PL, Toscani F, Menaca A, Gysels M, Ceulemans L, Simon ST, Pasman HRW, Albers G, Hall S, Murtagh FEM, Haugen DF, Downing J, Koffman J, Pettenati F, Finetti S, Antunes B, Harding R. Preferences for place of death if faced with advanced cancer: a population survey in England, Flanders, Germany, Italy, the Netherlands, Portugal and Spain. Ann Oncol 2012;23(8):2006-2015.
5. Gomes B, Higginson IJ. Factors influencing death at home in terminally ill patients with cancer: systematic review. BMJ 2006;332(7540):515-521.
6. Gruneir A, Mor V, Weitzen S, Truchil R, Teno J, Roy J. Where people die: a multilevel approach to understanding influences on site of death in America. Med Care Res Rev 2007;64(4):351-378.
7. Cohen J, Bilsen J, Addington-Hall J, Lofmark R, Miccinesi G, Kaasa S, Onwuteaka-Philipsen B, Deliens L. Population-based study of dying in hospital in six European countries. Palliat Med 2008;22(6):702-710.

8. Cohen J, Houttekier D, Onwuteaka-Philipsen B, Miccinesi G, Addington-Hall J, Kaasa S, Bilsen J, Deliens L. Which patients with cancer die at home? A study of six European countries using death certificate data. J Clin Oncol 2010;28(13):2267-2273.

9. Currow DC, Burns CM, Abernethy AP. Place of death for people with noncancer and cancer illness in South Australia: a population-based survey. J Palliat Care 2008;24(3):144-150.

10. Murtagh FEM, Bausewein C, Petkova H, Sleeman KE, Dodd RH, Gysels M, Johnston B, Murray S, Banerjee S, Shipman C, Hansford P, Wakefield D, Gomes B, Higginson IJ. Understanding place of death for patients with non malignant conditions: a systematic literature review. Final report. NIHR Service Delivery and Organisation Programme. 2012.

11. Tang ST, Huang EW, Liu TW, Rau KM, Hung YN, Wu SC. Propensity for home death among Taiwanese cancer decedents in 2001-2006, determined by services received at end of life. J Pain Symptom Manage 2010;40(4):566-574.

12. Abel J, Pring A, Rich A, Malik T, Verne J. The impact of advance care planning of place of death, a hospice retrospective cohort study. BMJ Support Palliat Care 2013;3(2):168-173.

13. Gomes B, Higginson IJ. Where people die (1974--2030): past trends, future projections and implications for care. Palliat Med 2008;22(1):33-41.

14. Mitchell SL, Teno JM, Miller SC, Mor V. A national study of the location of death for older persons with dementia. J Am Geriatr Soc 2005;53(2):299-305.

15. Macleod U. Place of death: is home always best? Br J Hosp Med (Lond) 2011;72(8):441-443.

16. Seale C, Addington-Hall J, McCarthy M. Awareness of dying: prevalence, causes and consequences. Soc Sci Med 1997;45(3):477-484.

17. Higginson I, Sarmento V, Calanzani N, Benalia H, Gomes B. Dying at home--is it better: a narrative appraisal of the state of the science. Palliat Med 2013;27(10):918-924.

18. Gott M, Small N, Barnes S, Payne S, Seamark D. Older people's views of a good death in heart failure: implications for palliative care provision. Soc Sci Med 2008;67(7):1113-1121.

19. Jordhoy MS, Fayers P, Saltnes T, Ahlner-Elmqvist M, Jannert M, Kaasa S. A palliative-care intervention and death at home: a cluster randomised trial. Lancet 2000;356(9233):888-893.

20. Barclay S, Case-Upton S. Knowing patients' preferences for place of death: how possible or desirable? Br J Gen Pract 2009;59(566):642-643.

21. Holdsworth L, Fisher S. A retrospective analysis of preferred and actual place of death for hospice patients. Int J Palliat Nurs 2010;16(9):424, 426, 428.

22. Paddy M. Influence of location on a good death. Nurs Stand 2011;26(1):33-36.

23. Davies E, Higginson IJ, eds. The solid facts: Palliative care. Geneva: World Health Organisation, 2004.

24. Department of Health. End of Life Care Strategy: Quality Markers and measures for end of life care. 2009. Available from http://webarchive.nationalarchives.gov.uk/20130107105354/http://www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsPolicyAndGuidance/DH_101681. Accessed 19th December 2014.

25. Teno JM, Gozalo PL, Bynum JPW, Leland NE, Miller SC, Morden NE, Scupp T, Goodman DC, Mor V. Change in end-of-life care for Medicare beneficiaries: site of death, place of care, and health care transitions in 2000, 2005, and 2009. JAMA 2013;309(5):470-477.

26. Agar M, Currow DC, Shelby-James TM, Plummer J, Sanderson C, Abernethy AP. Preference for place of care and place of death in palliative care: are these different questions? Palliat Med 2008;22(7):787-795.

27. Cohen J, Bilsen J, Hooft P, Deboosere P, van der Wal G, Deliens L. Dying at home or in an institution using death certificates to explore the factors associated with place of death. Health Policy 2006;78(2-3):319-329.

28. Thomas C, Morris SM, Clark D. Place of death: preferences among cancer patients and their carers. Soc Sci Med 2004;58(12):2431-2444.

29. van Gestel YRBM, Lemmens VEPP, Lingsma HF, de Hingh IHJT, Rutten HJT, Coebergh JW. The hospital standardized mortality ratio fallacy: a narrative review. Med Care 2012;50(8):662-667.

30. Abarshi E, Onwuteaka-Philipsen B, Donker G, Echteld M, Van den Block L, Deliens L. General practitioner awareness of preferred place of death and correlates of dying in a preferred place: a nationwide mortality follow-back study in the Netherlands. J Pain Symptom Manage 2009;38(4):568-577.

31. Beccaro M, Costantini M, Giorgi Rossi P, Miccinesi G, Grimaldi M, Bruzzi P. Actual and preferred place of death of cancer patients. Results from the Italian survey of the dying of cancer (ISDOC). J Epidemiol Community Health 2006;60(5):412-416.

32. Bell CL, Somogyi-Zalud E, Masaki KH. Factors associated with congruence between preferred and actual place of death. J Pain Symptom Manage 2010;39(3):591-604.

33. Brazil K, Howell D, Bedard M, Krueger P, Heidebrecht C. Preferences for place of care and place of death among informal caregivers of the terminally ill. Palliat Med 2005;19(6):492-499.

34. Ko W, Beccaro M, Miccinesi G, Van Casteren V, Donker G, Onwuteaka-Philipsen B, Miralles Espi M, Deliens L, Costantini M, Van den Block L. Awareness of general practitioners concerning cancer patients' preferences for place of death: evidence from four European countries. Eur J Cancer 2013;49(8):1967-1974.

35. Brogaard T, Neergaard MA, Sokolowski I, Olesen F, Jensen AB. Congruence between preferred and actual place of care and death among Danish cancer patients. Palliat Med 2013;27(2):155-164.

36. National Health Service. End of Life Care Quality Assessment (ELCQuA). 2011. Available from http://www.elcqua.nhs.uk/. Accessed 19th December 2014.

37. Barbera L, Paszat L, Chartier C. Death in hospital for cancer patients: an indicator of quality of end-of-life care. Palliat Med 2005;19(5):435-436.

38. Claessen SJJ, Francke AL, Belarbi HE, Pasman HR, van der Putten MJA, Deliens L. 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.

39. Earle CC, Park ER, Lai B, Weeks JC, Ayanian JZ, Block S. Identifying potential indicators of the quality of end-of-life cancer care from administrative data. J Clin Oncol 2003;21(6):1133-1138.

40. Peruselli C, Marinari M, Brivio B, Castagnini G, Cavana M, Centrone G, Magni C, Merlini M, Scaccabarozzi GL, Paci E. Evaluating a home palliative care service: development of indicators for a continuous quality improvement program. J Palliat Care 1997;13(3):34-42.

41. Campbell SM, Braspenning J, Hutchinson A, Marshall MN. Research methods used in developing and applying quality indicators in primary care. BMJ 2003;326(7393):816-819.

42. Donabedian A. The quality of care. How can it be assessed? JAMA 1988;260(12):1743-1748.

43. De Roo ML, Leemans K, Claessen SJJ, Cohen J, Pasman HR, Deliens L, Francke AL. Quality Indicators for Palliative Care: Update of a Systematic Review. J Pain Symptom Manage 2013;46(4):556-572.

44. Pasman HR, Brandt HE, Deliens L, Francke AL. Quality indicators for palliative care: a systematic review. J Pain Symptom Manage 2009;38(1):145-156.

45. Van den Block L, Van Casteren V, Deschepper R, Bossuyt N, Drieskens K, Bauwens S, Bilsen J, Deliens L. Nationwide monitoring of end-of-life care via the Sentinel Network of General Practitioners in Belgium: the research protocol of the SENTI-MELC study. BMC Palliat Care 2007;6:6.

46. Meeussen K, Van den Block L, Echteld MA, Boffin N, Bilsen J, Van Casteren V, Abarshi E, Donker G, Onwuteaka-Philipsen B, Deliens L. End-of-life care and circumstances of death in patients dying as a result of cancer in Belgium and the Netherlands: a retrospective comparative study. J Clin Oncol 2011;29(32):4327-4334.

47. Van den Block L, Onwuteaka-Philipsen B, Meeussen K, Donker G, Giusti F, Miccinesi G, Van Casteren V, Alonso T, Zurriaga O, Deliens L. Nationwide continuous monitoring of end-of-life care via representative networks of general practitioners in Europe. BMC Fam Pract 2013;14(1):73.

48. Vega Alonso AT, Zurriaga Llorens O, Galmes Truyols A, Lozano Alonso JE, Paisan Maestro L, Gil Costa M, Herrero Llorente A, Ramos Aceitero JM. [Guide to the principles and methods of health sentinel networks in Spain]. Gac Sanit 2006;20 Suppl 3:52-60.

49. Deckers JGM, Paget WJ, Schellevis FG, Fleming DM. European primary care surveillance networks: their structure and operation. Fam Pract 2006;23(2):151-158.

50. Hoek JF, Ribbe MW, Hertogh CMPM, van der Vleuten CPM. The role of the specialist physician in nursing homes: the Netherlands' experience. Int J Geriatr Psychiatry 2003;18(3):244-249.

51. Abarshi E, Echteld M, Donker G, Van den Block L, Onwuteaka-Philipsen B, Deliens L. Discussing end-of-life issues in the last months of life: a nationwide study among general practitioners. J Palliat Med 2011;14(3):323-330.

52. Meeussen K, Van den Block L, Bossuyt N, Bilsen J, Echteld M, Van Casteren V, Deliens L. GPs' awareness of patients' preference for place of death. Br J Gen Pract 2009;59(566):665-670.

53. Aabom B, Kragstrup J, Vondeling H, Bakketeig LS, Stovring H. Population-based study of place of death of patients with cancer: implications for GPs. Br J Gen Pract 2005;55(518):684-689.

54. Fukui S, Kawagoe H, Masako S, Noriko N, Hiroko N, Toshie M. Determinants of the place of death among terminally ill cancer patients under home hospice care in Japan. Palliat Med 2003;17(5):445-453.

55. Houttekier D, Cohen J, Van den Block L, Bossuyt N, Deliens L. Involvement of palliative care services strongly predicts place of death in Belgium. J Palliat Med 2010;13(12):1461-1468.

56. Howat A, Veitch C, Cairns W. A retrospective review of place of death of palliative care patients in regional north Queensland. Palliat Med 2007;21(1):41-47.

57. Saugo M, Pellizzari M, Marcon L, Benetollo P, Toffanin R, Gallina P, Cecchetto G, Miccinesi G, Rigon S, Cancian M, Sichetti D. Impact of home care on place of death, access to emergency departments and opioid therapy in 350 terminal cancer patients. Tumori 2008;94(1):87-95.

58. Ministerie van Volksgezondheid WeS. Verankering van palliatieve zorg in de praktijk [Embedding of Palliative Care in Practice]. [In Dutch]. 2011. Available from http://www.rijksoverheid.nl/documenten-en-publicaties/kamerstukken/2011/01/14/verankering-van-palliatieve-zorg-in-de-praktijk.html. Accessed 19th December 2014.

59. Council of Europe. Recommendation Rec (2003) 24 of the Committee of Ministers to member states on the organisation of palliative care. CM 2003;130. Available from http://www.coe.int/T/DG3/Health/Source/Rec(2003)24_en.pdf. Accessed 19th December 2014.

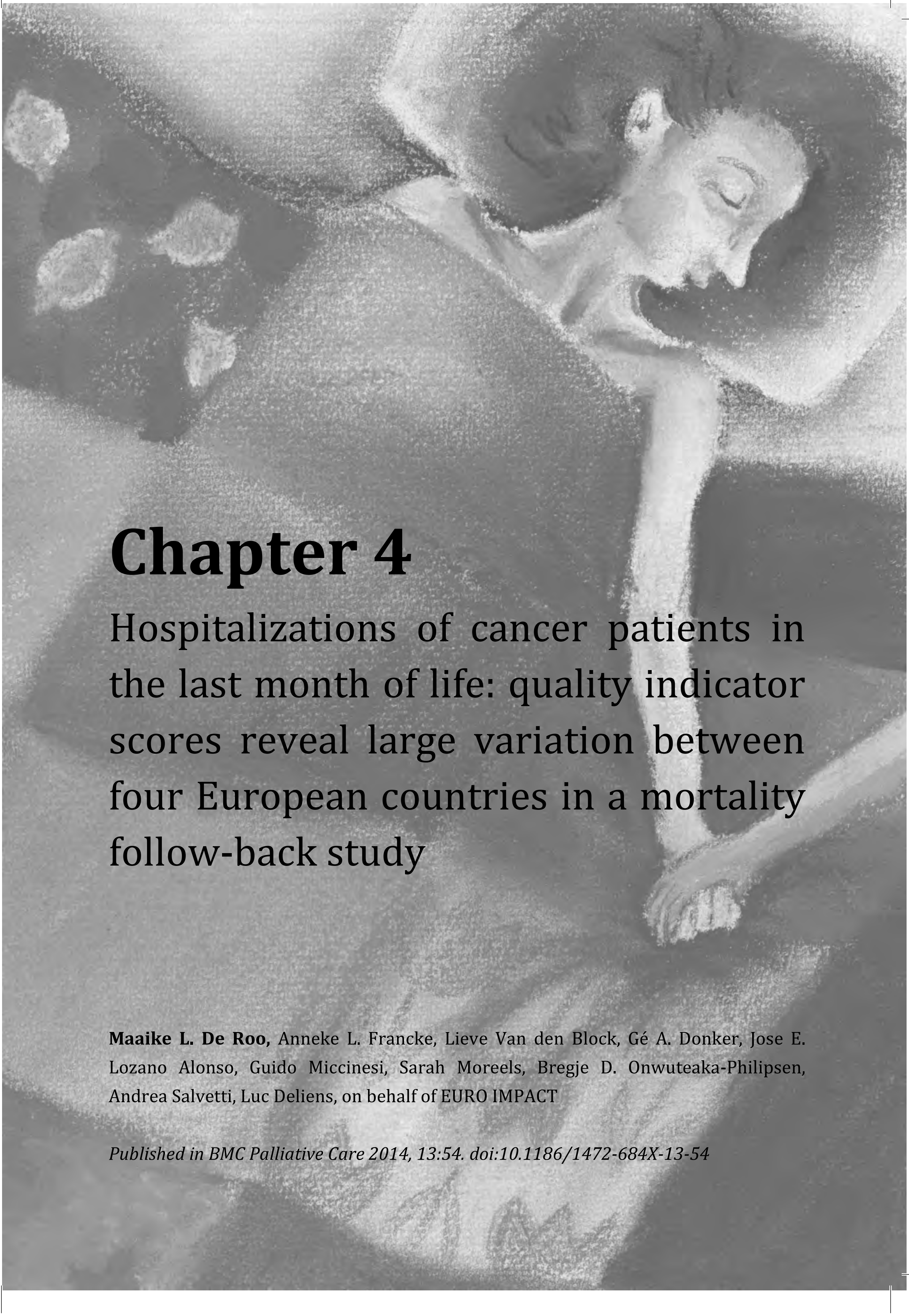
60. IIS. Atención a Los Cuidados Paliativos: Organización en Las Comunidades Autónomas. Madrid: Instituto de Información Sanitaria - Sistema de Información de Atención Primaria (SIAP) - Ministerio de Sanidad y Politica Social, Gobierno de Espana. 2009.

61. Desmedt M, Michel H. Palliative home care: improving co-operation between the specialist team and the family doctor. Support Care Cancer 2002;10(4):343-348.

62. Sbanotto A, Burnhill R. Palliative care in Italy: the current situation. Support Care Cancer 1998;6(5):426-429.

63. Costantini M, Toscani F, Gallucci M, Brunelli C, Miccinesi G, Tamburini M, Paci E, Di Giulio P, Peruselli C, Higginson I, Addington-Hall J. Terminal cancer patients and timing of referral to palliative care: a multicenter prospective cohort study. Italian Cooperative Research Group on Palliative Medicine. J Pain Symptom Manage 1999;18(4):243-252.

64. Hannon KL, Lester HE, Campbell SM. Recording patient preferences for end-of-life care as an incentivized quality indicator: what do general practice staff think? Palliat Med 2012;26(4):336-341.



# Chapter 4

## Hospitalizations of cancer patients in the last month of life: quality indicator scores reveal large variation between four European countries in a mortality follow-back study

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## ABSTRACT

**BACKGROUND –** Repeated and long hospitalizations of cancer patients at the end of life have been suggested as indicators of low quality of palliative care. Comparing the care delivered between different countries with the help of these quality indicators may identify opportunities to improve practice. Our objective is twofold: firstly, to describe the scores for the existing quality indicators “the percentage of time spent in hospital” and “the proportion of adult patients with more than one hospitalization in the last 30 days of life” in populations of cancer patients in four European countries and to see whether these countries met previously defined performance standards; secondly, to assess whether these scores are related to receiving palliative care from their GP.

**METHODS –** A mortality follow-back study was conducted, based on data recorded by representative GP networks for samples of cancer patients living at home who died non-suddenly in Belgium (n=500), the Netherlands (n=310), Italy (n=764), and Spain (n=224).

**RESULTS –** The quality indicator score for “the percentage of time spent in hospital” in the last month of life was 14.1% in the Netherlands, 17.7% in Spain, 22.2% in Italy, and 24.6% in Belgium, which means that none of the countries met the performance standard of <10%. For the “proportion of patients with more than one hospitalization in the last 30 days of life”, two countries met the performance standard of <4%: the Netherlands (0.6%) and Italy (3.1%). Spain had a score of 4.0% and Belgium scored 5.4%. When patients received palliative care from their GP, significantly less time was spent in hospital in the last month and fewer hospitalizations took place.

**CONCLUSIONS –** European countries differ regarding the frequency and duration of hospitalizations of cancer patients in the last month of life. This reflects country-specific differences in the organization of palliative care and highlights the important role of the GP in palliative care provision.

## BACKGROUND

High rates of hospitalization at the end of life may be an indication that palliative care is of suboptimal quality, since these hospitalizations can be associated with offering aggressive and futile treatments,[1,2] with too much focus on life prolongation rather than the patient's quality of life and the relief of symptom burden, with inadequate communication about the patient's care preferences or with the limited availability or use of palliative home-care services.[3] Although some hospitalizations may be inevitable,[4,5] there may be potential to reduce the number and duration of hospitalizations,[6] e.g. by providing appropriate support from general practitioners.[1,7]

Long or repeated hospital admissions at the end of life have been suggested as indicators that palliative care is of a poor quality.[1,8,9] Several quality indicators for palliative care concerning the frequency and duration of hospitalizations at the end of life have already been developed.[1,9-12] Measuring these quality indicators can give insights into areas where the quality of care is not optimal, subsequently enabling priorities to be set for quality improvement.[12] In this study, we used two quality indicators regarding hospitalizations, selected specifically because they could be derived from the existing data records of general practitioners (GPs) in Belgium, the Netherlands, Italy, and Spain. The first is "the percentage of time spent in hospital", coming from a set of quality indicators developed in Italy for palliative home care.[9] The second quality indicator used concerns "the proportion with more than one hospitalization in the last 30 days of life". This quality indicator is part of an indicator set that was developed in the United States for cancer patients.[1,10,11] These indicators have specific performance standards: namely that less than 4% of cancer patients should have more than one hospitalization in the last month of life[10] and that less than 10% of time should be spent in hospital.[9] Using these existing indicators, instead of constantly developing new indicators for palliative care offers advantages. In this case, deriving these indicators from data collected by existing registrations by GPs, we further tested the usefulness of these indicators in international comparative research.

Comparing the care delivered between different countries may help identify opportunities to improve practice,[13] particularly when the comparison includes an investigation of the factors that are associated with poor or better quality indicator scores. In this paper, we therefore also look at whether there is a relationship with the delivery of palliative care by GPs. Previous studies have shown that the provision of palliative care by GPs is associated with less time spent in hospital and fewer hospitalizations.[4,5] It is also important to examine whether there is a relationship with GP provision of palliative care because the roles of GPs differ between countries. In some countries, like the Netherlands and Spain, GPs function as gatekeepers[14] to hospital care: except in very acute situations, patients need a formal referral from the GP to see a medical specialist in a hospital. Hence, this provides an opportunity for preventing avoidable hospitalizations. Although GPs in Belgium and Italy do not have this strict gatekeeper function, they are still central professionals in the healthcare system and have a coordinating role, since most people have their "own" GP whom they consult when they have medical problems.[15] Another aspect of the GP's function that differs between countries is their role in the provision of palliative care. In the Netherlands, the GP plays a central role in the delivery of generalist palliative care at home.[16-18] In the other three countries, the GP shares the responsibility of palliative care delivery with generalist or specialist palliative-care home teams.[14,15,18-20]

This paper addresses the following research questions:

- What is (a) the percentage of time spent in hospital in the last month of life, and (b) the proportion of cancer patients with more than one hospitalization in the last 30 days of life who lived at home and who died non-suddenly in Belgium, the Netherlands, Italy, or Spain?
- Do the countries meet the performance standards defined for these two quality indicators?
- Do these quality indicator scores differ between the cancer patients who received palliative care from their general practitioner and those who did not receive palliative care from their GP?

## METHODS

### Study design

This paper is based on data from the European Sentinel GP Networks Monitoring End-of-Life Care (EURO SENTI-MELC) study, a mortality follow-back study on monitoring end-of-life care in Belgium, the Netherlands, Spain, and Italy. For this study, we used data from the nationally representative GP networks[14] collected in 2009 (all countries except Spain), 2010 (all four countries) and 2011 (Spain only). The GP sentinel networks cover 1.8% and 0.8% of the Belgian and Dutch national populations respectively.[14,21,22] In Spain, the two sentinel networks involved in this study account for 3.5% of the patient population in the Castilla y León region (in the northwest) and 2.2% in the Comunitat Valenciana region (in the east).[14,23] The Italian data came from a new GP network set up for this study[24] and were collected from nine of the 146 health districts, covering about 4% of the national patient population.[14] The participating GPs in all four countries were representative for the general population of GPs in each country (or health districts in Italy and regions in Spain) in terms of age, gender, and geographical distribution.[14,25,26]

### Study population

Since one of the two quality indicators selected was developed for a cancer population and the other for a population receiving home care, we decided to focus on a population of cancer patients who lived at home in the last month of life. The data were analyzed of deceased adult cancer patients (aged 18 and above), who had died non-suddenly according to their GP. Since this study examines the care delivered at the end of life, the data of people who died suddenly and unexpectedly according to their GP were excluded, leaving a population that was eligible for palliative care.[21] (Figure 1 shows a flowchart of the selected sample.)

### Data collection

In the EURO SENTI-MELC study, GPs recorded the characteristics of recently deceased patients on a weekly basis using a standardized questionnaire. Recall bias was minimized by requiring data entry to be no more than one week after the GP had been informed of the patient’s death.[14] In the questionnaire, GPs were asked about the place of death and place(s) of residence in the last three months before death, as well as the length of stay in specific care settings in the last 30 days before death. Thus, the number of hospitalizations and the length of stay in hospital in the last month of life could be deduced. GPs were asked to indicate whether they provided palliative care by the following question: “Did you provide palliative care to this patient?” [“no”; “yes, but not until death”; “yes, until death” (dichotomized into “yes” and “no”)].

### Informed consent and patient anonymity

After being informed of the objectives and procedures of the study, participating GPs gave written informed consent at the beginning of each registration year. Strict procedures regarding patient anonymity were employed during data collection and entry; every patient was assigned an anonymous reference code by their GP and any identifying patient and GP data (such as date of birth, postcode, and GP identification number) were replaced with aggregate categories or anonymous codes.

### Ethical approval

The protocol of this study was approved by the Ethical Review Board of Brussels University Hospital of the Vrije Universiteit Brussel (2004), Belgium, and the Local Ethical Committee, "Comitato Etico della Azienda U.S.L. n. 9 di Grosseto" (2008), Tuscany, Italy. In the Netherlands and Spain, no ethical approval is required for the posthumous collection of anonymous patient data.

### Statistical analysis

The quality indicator "the percentage of time spent in hospital" is calculated using "number of days in hospital during home palliative care" as the numerator and "the total number of days of home palliative care" as the denominator. The performance standard "less than 10% of time should be spent in hospital"[9] was originally specified for patients who received home palliative care. In this study, it is calculated for the last month of life, for cancer patients regardless of whether they received home palliative care. The second quality indicator, "the proportion with more than one hospitalization in the last 30 days of life", was calculated using "the number of patients who died from cancer and had more than one hospitalization in the last 30 days of life" as the numerator and "the number of patients who died from cancer" as the denominator. We used the original performance standard: "less than 4% of cancer patients should have more than one hospitalization in the last month of life".[10]

To enable a valid comparison between countries, the quality indicator scores were standardized for patients' gender, age at death, and cancer type, using the distribution observed in the study population as a whole as the reference distribution.

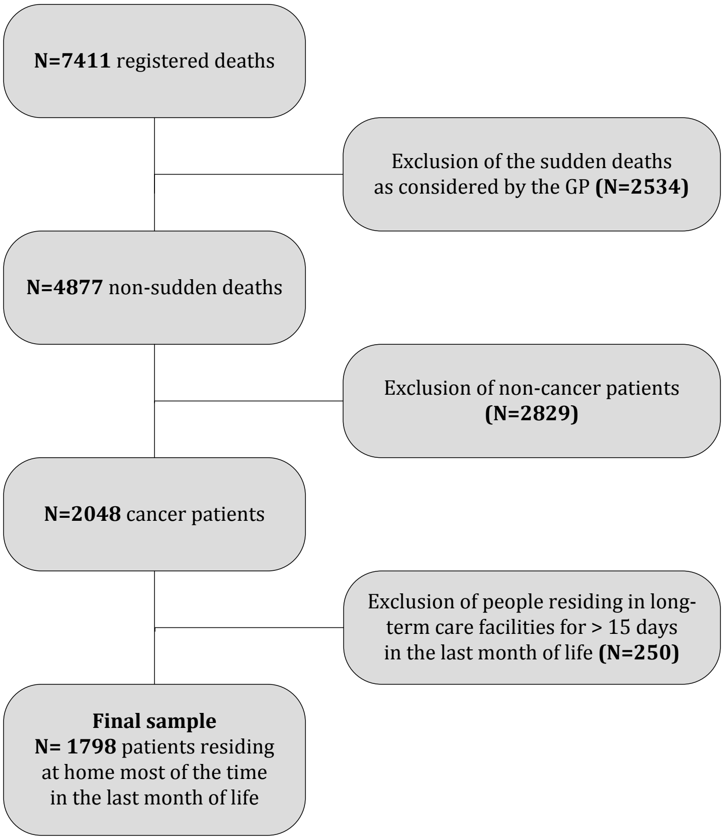
To test whether these quality indicator scores differed significantly between the patients who received palliative care from their GP and those who did not, we used a Mann Whitney U test for "the percentage of time spent in hospital" and a Fisher's Exact test for "the proportion with more than one hospitalization in the last 30 days of life". Standardization of the quality indicator scores to enable valid comparison between the two groups was not applied, since the two groups did not differ significantly in terms of gender, age at death, and cancer type. The analyses were performed using IBM SPSS Statistics software, Version 20.0 (IBM Corp., 2011, Armonk, NY), with significance level $\alpha < 0.05$.

## RESULTS

### Description of the sample

The total sample in this study consisted of 1798 patients: 500 for Belgium, 310 for the Netherlands, 764 for Italy and 224 for Spain (see Figure 1).

**Figure 1 – Flowchart of the sample selection**



In all countries, the majority of the patients in the samples were male. About one fifth of the Italian and Spanish samples were aged 85 or older, whereas this group of the very elderly was smaller in Belgium (13.9%) and the Netherlands (11.3%) (Table 1). Lung cancer and colorectal cancer were the most common types of cancer in all four countries. The proportion of cancer patients in each country receiving palliative care from their GP ranged from 61.4% (Belgium) to 73.9% (the Netherlands) (Table 1).

**Table 1 – Characteristics of study population per country (N=1798)**

| | BELGIUM (N=500) N (%) | NETHERLANDS (N=310) N (%) | ITALY (N=764) N (%) | SPAIN (N=224) N (%) |
|---|---|---|---|---|
| **Gender** * | | | | |
| Female | 210 (42.0) | 138 (44.8) | 344 (45.0) | 69 (31.1) |
| Male | 290 (58.0) | 170 (55.2) | 420 (55.0) | 153 (68.9) |
| **Age at death** † | | | | |
| 18-64 years | 150 (30.3) | 88 (28.4) | 180 (23.6) | 51 (22.8) |
| 65-84 years | 276 (55.8) | 187 (60.3) | 430 (56.3) | 132 (58.9) |
| 85 years and older | 69 (13.9) | 35 (11.3) | 154 (20.2) | 41 (18.3) |
| **Cancer type** ‡ | | | | |
| Lung cancer | 135 (27.0) | 78 (26.4) | 174 (27.6) | 44 (20.2) |
| Breast cancer | 39 (7.8) | 30 (10.2) | 51 (8.1) | 11 (5.0) |
| Colorectal cancer | 59 (11.8) | 34 (11.5) | 92 (14.6) | 42 (19.3) |
| Prostate cancer | 20 (4.0) | 22 (7.5) | 30 (4.8) | 22 (10.1) |
| Other | 247 (49.4) | 131 (44.4) | 283 (44.9) | 99 (45.4) |
| **GP provided palliative care** § | | | | |
| No | 193 (38.6) | 79 (26.1) | 277 (36.3) | 62 (28.8) |
| Yes | 307 (61.4) | 224 (73.9) | 486 (63.7) | 153 (71.2) |

* Missing values: Belgium no missing values, the Netherlands N=2, Italy no missing values, Spain N=2.

† Missing values: Belgium N=5, the Netherlands, Italy and Spain no missing values.

‡ Missing values: Belgium no missing values, the Netherlands N=15, Italy N=134, Spain N=6.

§ Missing values: Belgium no missing values, the Netherlands N=7, Italy N=1, Spain N=9.

Overall, GPs knew where the patient was residing in the last 30 days of life in 96% of the cases. The percentage of GPs who did not know where the patient resided was lowest in the Netherlands (1%), and highest in Spain (14%). GPs in Belgium and Italy did not know where the patient resided in the last month of life for 3% of their patients (not shown in Tables).

### Quality indicator "the percentage of time spent in hospital"

The Netherlands had the lowest percentage of time spent in hospital in the last month of life (14.1%), and Belgium the highest percentage (24.6%) (Table 2). If we compare quality indicator scores between the cancer patient group who did receive GP palliative care and the group who did not, we see that in all countries the quality indicator scores are significantly lower, i.e. less time was spent in hospital, for the group that received GP palliative care (Table 2). Only the group of cancer patients who received palliative care from their GP in the Netherlands met the performance standard of 10%, as they spent only 7.5% of their last month in hospital.

**Table 2 – Quality indicator scores per country and comparing cancer patients who received palliative care from their GP and those who did not**

| | “Percentage of time spent in hospital” in the last month of life (%) | | | | “Proportion with more than one hospitalization in the last 30 days of life” (%) | | | |
|---|---|---|---|---|---|---|---|---|
| **Performance Standard** [*,†] | <10% | | | | <4% | | | |
| | **BE** | **NL** | **IT** | **ES** | **BE** | **NL** | **IT** | **ES** |
| **Total population per country** [‡] | 24.6 | 14.1 | 22.2 | 17.7 | 5.4 | 0.6 | 3.1 | 4.0 |
| **Did not receive palliative care from the GP** [§] | 39.7[‖] | 34.7[‖] | 29.3[‖] | 32.3[‖] | 8.3 | 1.3 | 5.1[¶] | 8.1 |
| **Received palliative care from the GP** [§] | 16.1[‖] | 7.5[‖] | 18.7[‖] | 11.8[‖] | 4.2 | 0.4 | 2.1[¶] | 3.3 |

BE= Belgium, NL= the Netherlands, IT= Italy, ES= Spain

* Performance standard for the quality indicator “the percentage of time spent in hospital” in the last month of life is 10%.[9]

† Performance standard for the for the quality indicator “the percentage of patients who had more than 1 hospitalization in the last month of life” is 4%.[1,10,11]

‡ These percentages are standardized for gender, age and cancer type.

§ These percentages are not standardized for gender, age and cancer type, since these characteristics did not differ significantly between the two groups in each country.

|| Mann Whitney U test showed significant difference, p<0.001.

¶ Fisher’s Exact test showed significant difference, p< 0.05.

### Quality indicator “the proportion with more than one hospitalization in the last 30 days of life”

The Netherlands had the lowest proportion with more than one hospitalization in the final month of life (0.6%), followed by Italy (3.1%). Spain (4.0%) and Belgium (5.4%) had a higher proportion of multiple hospitalizations (Table 2). The performance standard of less than 4% was thus met in two countries: the Netherlands and Italy (Table 2).

There were fewer rehospitalizations among the group of cancer patients who received GP palliative care, although a significant difference was only found in Italy (Table 2). The performance standard of 4% was met for the patients receiving GP palliative care in three countries: the Netherlands (0.4%), Italy (2.1%), and Spain (3.3%). The Belgian score of 4.2% almost met the performance standard. In the Netherlands, the performance standard was also met for the group of patients who did not receive palliative care from their GP (Table 2).

## DISCUSSION

The percentage of time spent in hospital during the last month of life varied between the four countries, ranging from 14.1% (the Netherlands) to 24.6% (Belgium), while the proportion of patients with more than one hospitalization ranged from 0.6% (the Netherlands) to 5.4% (Belgium). The group of patients who received palliative care from their GP spent significantly less time in hospital and had fewer hospitalizations in the last month of life.

The original studies presenting these quality indicators[1,9-11] also specified a performance standard. For the indicator concerning the time spent in hospital in the last month of life, none of the four countries met the performance standard (i.e. less than 10% of time should be spent in hospital) in our study. One could argue that we did not evaluate the performance of home palliative care, as was the case in the original study in Italy[9] and therefore cannot apply this this performance standard to our data, because while patients were living at home in our study, they were not necessarily receiving home palliative care. Nevertheless, even when we calculated the quality indicator scores for the patients who received palliative care from their GP, only the Netherlands (7.5%) met this performance standard. This could raise the question of whether a new performance standard needs to be defined when measuring this quality indicator nationwide. In this case, an alternative could be to apply the “best-practice norm” principle: take the best-scoring country’s score as the target other countries should aim for in the future.

For the other indicator, concerning the percentage of cancer patients who were hospitalized more than once in the last month of life, the performance standard (i.e. less than 4% of cancer patients should have more than one hospitalization in the last month of life) was not achieved in two of the four countries in our study (i.e. Spain and Belgium, with 4.0% and 5.4% of patients respectively having more than one hospitalization in the last month). This suggests this performance standard is a feasible goal and can be used as such in the future. The performance standard could even be updated following repeated measurements of these quality indicators, resulting in continuous quality improvement.[10]

The between-country differences in quality indicator scores found in this study may reflect differences between these countries in the organization of palliative care. One of these differences may be the role of the GP in the provision of health care in general, and especially in the provision of palliative care. The high degree of responsibility assigned to GPs in the Netherlands, both as general gatekeepers[14] and specifically in the delivery of palliative care,[16,17] could be a reason for the fact that hospitalizations in the Netherlands are shorter and rehospitalizations are less frequent. Spain and Belgium have comparable rates, suggesting that the general gatekeeper function of the GP in Spain[14] may not have as much effect on hospitalizations as the fact that the organization of palliative care is the shared responsibility of both GPs and palliative home-care teams.[27] The latter is also the case in Belgium.[15] Despite the fact that in Italy palliative home care is mainly provided by multidisciplinary home teams,[18,19] the percentage of time spent in hospital in Italy is relatively high: 22.2%. Another study following an Italian cohort and US cohort in the year after the diagnosis of cancer revealed that the number of hospital admissions was the same in both countries but the mean number of days spent in hospital in Italy was double that of the US cohort.[13] Two potential causes were suggested: the fact that in Italy patients also stay in hospital for e.g. pre-intervention diagnostic tests, whereas in the US these tests were performed in an out-patient setting; and the fact that hospice programs in the US are more established than in Italy, possibly resulting in a higher number of hospitalizations for end-of-life care in Italy.[13]

This is in line with the important finding of this study that among the group of patients where the GP provided palliative care, less time was spent in hospital in the last month of life, and multiple hospitalizations were less frequent. We cannot provide insight into the causality in this association due to the design of the study. It might be that patients could stay at home because they insisted on staying at home, had an informal caregiver at home, or had a low symptom burden, and therefore were in the right place to get palliative care from their GP. Nevertheless, this finding highlights the importance of the GP in the organization of palliative care, and the challenge for the GP and home-care services to reduce the number of potentially avoidable hospitalizations.

**Strengths and limitations**

This is the first cross-national study using existing data to compare the length and number of hospitalizations in the last month of life, and to assess their function as quality indicators. A strength of the study is that it seems feasible to calculate the scores of these two quality indicators based on data gathered by GPs, as GPs knew where the patient was residing in the last 30 days of life in 96% of the non-sudden cancer deaths. Consequently, existing GP networks are a feasible candidate for a continuous monitor of some aspects of the quality of palliative care. Nevertheless, there are limitations when using GP networks to collect data. We cannot fully exclude the inaccurate judgment by GPs of patient deaths as being sudden and unexpected.

There may be a bias as GPs may not have been informed or aware of all transfers of the patient to and from hospital or they missed some transitions in the course of recording the data. Due to the anonymous coding of the data collected in the GP networks, we could not validate this information with hospital registries or insurance data. To minimize recall bias, GPs reported on a weekly basis.

Furthermore we do not have information on the reason for hospitalizations in the last month, because we used data recorded by existing GP networks, which did not contain information on this subject. For the same reason, we cannot provide information about whether these hospitalizations were elective or via the emergency department, nor whether they were potentially avoidable or unavoidable. In addition, the availability of hospices and palliative care units might influence whether patients are hospitalized or not in the last month of life. The existing registrations used in this study did not provide any data on the availability of hospices and palliative care units and whether patients with uncontrolled symptoms may have no choice but to be hospitalized. Further research could examine these issues more in-depth.

Another limitation is that GPs themselves stated whether they had provided palliative care and we could not examine the validity of this self-reported palliative care provision. We have no detailed information on what GPs considered as “providing palliative care” and were therefore unable to verify whether these definitions were consistent with existing expert definitions. Some GPs may consider care for patients with chronic diseases as palliative care, whereas other consider this as regular GP care. Therefore this study reflects the delivery of what GPs themselves perceive to be palliative care. However, as our study is limited to deceased *cancer* patients, inter-doctor variation is less likely than would be the case in a study of all deceased patients.

## CONCLUSION

“The percentage of time spent in hospital” in the last month of life and “the proportion with more than one hospitalization in the last 30 days of life” are quality indicators that can be collected with the use of existing sentinel networks of GPs. Quality indicator scores reveal substantial differences between countries, reflecting country-specific differences in the organization of palliative care. In the group of patients who received palliative care from their GP, there were fewer hospitalizations and significantly less time was spent in hospital in the last month, highlighting the important role of the GP in palliative care provision.

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## REFERENCES

1. Earle CC, Park ER, Lai B, Weeks JC, Ayanian JZ, Block S. Identifying potential indicators of the quality of end-of-life cancer care from administrative data. J Clin Oncol 2003;21(6):1133-1138.
2. Mezey M, Dubler NN, Mitty E, Brody AA. What impact do setting and transitions have on the quality of life at the end of life and the quality of the dying process? Gerontologist 2002;42 Spec No 3:54-67.
3. Earle CC, Landrum MB, Souza JM, Neville BA, Weeks JC, Ayanian JZ. Aggressiveness of cancer care near the end of life: is it a quality-of-care issue? J Clin Oncol 2008;26(23):3860-3866.
4. Van den Block L, Deschepper R, Drieskens K, Bauwens S, Bilsen J, Bossuyt N, Deliens L. Hospitalisations at the end of life: using a sentinel surveillance network to study hospital use and associated patient, disease and healthcare factors. BMC Health Serv Res 2007;7:69.
5. Abarshi E, Echteld M, Van den Block L, Donker G, Deliens L, Onwuteaka-Philipsen B. Transitions between care settings at the end of life in the Netherlands: results from a nationwide study. Palliat Med 2010;24(2):166-174.
6. Gott M, Frey R, Robinson J, Boyd M, O'Callaghan A, Richards N, Snow B. The nature of, and reasons for, 'inappropriate' hospitalisations among patients with palliative care needs: A qualitative exploration of the views of generalist palliative care providers. Palliat Med 2013;27(8):747-756.
7. Hjermstad MJ, Kolflaath J, Lokken AO, Hanssen SB, Normann AP, Aass N. Are emergency admissions in palliative cancer care always necessary? Results from a descriptive study. BMJ Open 2013;3:e002515
8. Barbera L, Paszat L, Qiu F. End-of-life care in lung cancer patients in Ontario: aggressiveness of care in the population and a description of hospital admissions. J Pain Symptom Manage 2008;35(3):267-274.
9. Peruselli C, Marinari M, Brivio B, Castagnini G, Cavana M, Centrone G, Magni C, Merlini M, Scaccabarozzi GL, Paci E. Evaluating a home palliative care service: development of indicators for a continuous quality improvement program. J Palliat Care 1997;13(3):34-42.
10. Earle CC, Neville BA, Landrum MB, Souza JM, Weeks JC, Block SD, Grunfeld E, Ayanian JZ. Evaluating claims-based indicators of the intensity of end-of-life cancer care. Int J Qual Health Care 2005;17(6):505-509.
11. National Quality Forum. National voluntary consensus standards for symptom management and end-of-life care in cancer patients. 2006. Available from http://www.qualityforum.org/. Accessed 19th December 2014.
12. De Roo ML, Leemans K, Claessen SJJ, Cohen J, Pasman HR, Deliens L, Francke AL. Quality Indicators for Palliative Care: Update of a Systematic Review. J Pain Symptom Manage 2013;46(4):556-572.
13. Gigli A, Warren JL, Yabroff KR, Francisci S, Stedman M, Guzzinati S, Giusti F, Miccinesi G, Crocetti E, Angiolini C, Mariotto A. Initial treatment for newly diagnosed elderly colorectal cancer patients: patterns of care in Italy and the United States. J Natl Cancer Inst Monogr 2013;2013(46):88-98.
14. Van den Block L, Onwuteaka-Philipsen B, Meeussen K, Donker G, Giusti F, Miccinesi G, Van Casteren V, Alonso T, Zurriaga O, Deliens L. Nationwide continuous monitoring of end-of-life care via representative networks of general practitioners in Europe. BMC Fam Pract 2013;14(1):73.
15. Desmedt M, Michel H. Palliative home care: improving co-operation between the specialist team and the family doctor. Support Care Cancer 2002;10(4):343-348.
16. Ministerie van Volksgezondheid WeS. Verankering van palliatieve zorg in de praktijk [Embedding of Palliative Care in Practice]. [In Dutch]. 2011. Available from http://www.rijksoverheid.nl/documenten-en-publicaties/kamerstukken/2011/01/14/verankering-van-palliatieve-zorg-in-de-praktijk.html. Accessed 19th December 2014.
17. Council of Europe. Recommendation Rec (2003) 24 of the Committee of Ministers to member states on the organisation of palliative care. CM 2003;130. Available from http://www.coe.int/T/DG3/Health/Source/Rec(2003)24_en.pdf. Accessed 19th December 2014.

18. Sbanotto A, Burnhill R. Palliative care in Italy: the current situation. Support Care Cancer 1998;6(5):426-429.

19. Costantini M, Toscani F, Gallucci M, Brunelli C, Miccinesi G, Tamburini M, Paci E, Di Giulio P, Peruselli C, Higginson I, Addington-Hall J. Terminal cancer patients and timing of referral to palliative care: a multicenter prospective cohort study. Italian Cooperative Research Group on Palliative Medicine. J Pain Symptom Manage 1999;18(4):243-252.

20. Abarshi E, Echteld MA, Van den Block L, Donker G, Bossuyt N, Meeussen K, Bilsen J, Onwuteaka-Philipsen B, Deliens L. Use of palliative care services and general practitioner visits at the end of life in The Netherlands and Belgium. J Pain Symptom Manage 2011;41(2):436-448.

21. Van den Block L, Van Casteren V, Deschepper R, Bossuyt N, Drieskens K, Bauwens S, Bilsen J, Deliens L. Nationwide monitoring of end-of-life care via the Sentinel Network of General Practitioners in Belgium: the research protocol of the SENTI-MELC study. BMC Palliat Care 2007;6:6.

22. Meeussen K, Van den Block L, Echteld MA, Boffin N, Bilsen J, Van Casteren V, Abarshi E, Donker G, Onwuteaka-Philipsen B, Deliens L. End-of-life care and circumstances of death in patients dying as a result of cancer in Belgium and the Netherlands: a retrospective comparative study. J Clin Oncol 2011;29(32):4327-4334.

23. Vega Alonso AT, Zurriaga Llorens O, Galmes Truyols A, Lozano Alonso JE, Paisan Maestro L, Gil Costa M, Herrero Llorente A, Ramos Aceitero JM. [Guide to the principles and methods of health sentinel networks in Spain]. Gac Sanit 2006;20 Suppl 3:52-60.

24. Deckers JGM, Paget WJ, Schellevis FG, Fleming DM. European primary care surveillance networks: their structure and operation. Fam Pract 2006;23(2):151-158.

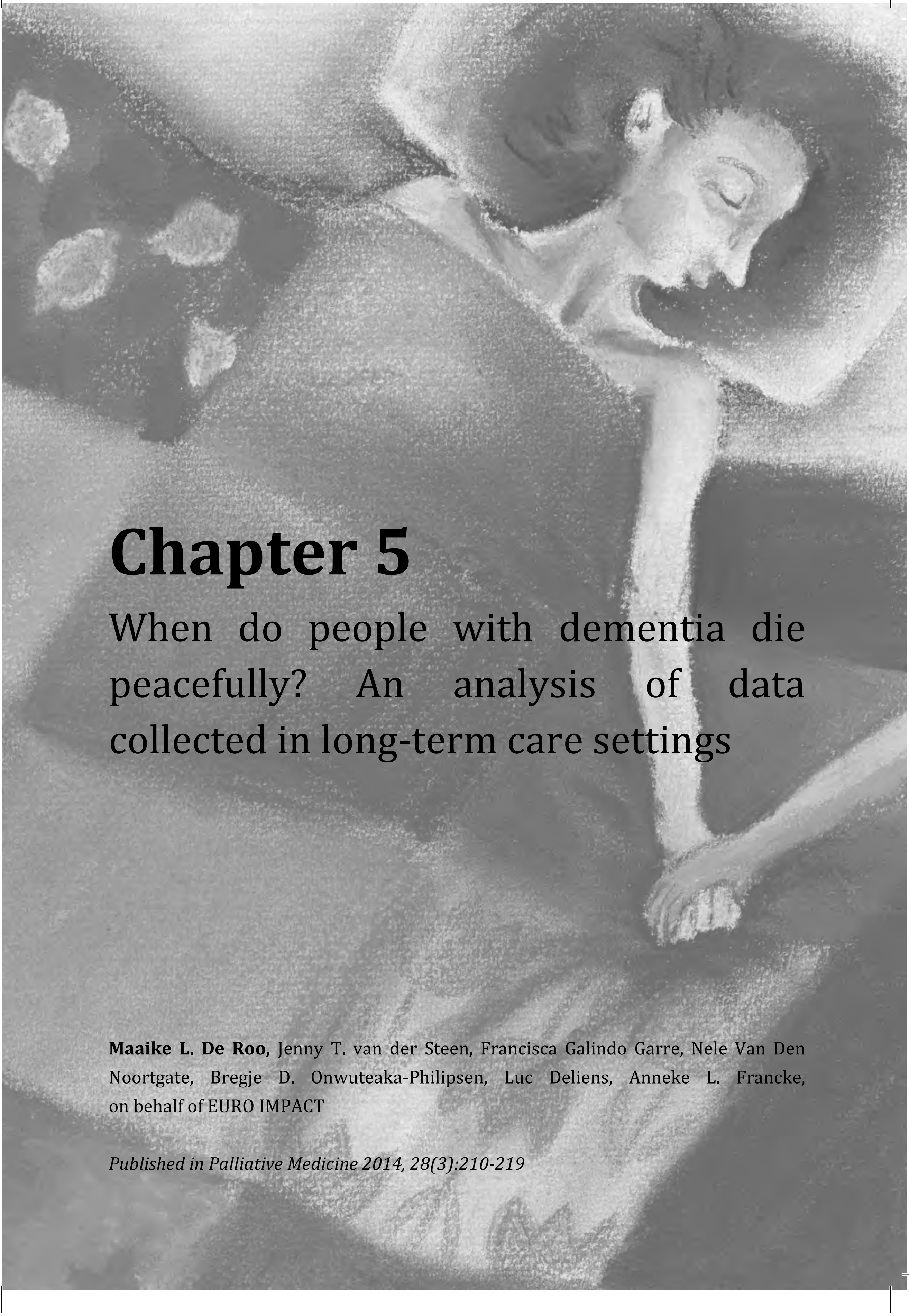
25. Donker GA. Continuous Morbidity Registration Dutch Sentinel General Practice Network 2010. Annual report. Utrecht: NIVEL, 2011. Available from www.nivel.nl/peilstations. Accessed 19th December 2014.

26. Boffin N, Moreels S, Van Casteren V. The Belgian Network of Sentinel General Practices Between 2007 and 2012: A Short Report. Brussels: Scientific Institute of Public Health, 2013.

27. IIS. Atención a Los Cuidados Paliativos: Organización en Las Comunidades Autónomas. Madrid: Instituto de Información Sanitaria - Sistema de Información de Atención Primaria (SIAP) - Ministerio de Sanidad y Politica Social, Gobierno de Espana. 2009.

# PART 3

## Quality Indicators for Palliative Care for Residents with Dementia in Long-Term Care Facilities



# Chapter 5

## When do people with dementia die peacefully? An analysis of data collected in long-term care settings

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## ABSTRACT

**BACKGROUND –** Little is known about dying peacefully with dementia in long-term care facilities. Dying peacefully may be influenced by characteristics of the palliative care provided and characteristics of the long-term care setting. If so, dying peacefully may serve as a quality indicator for palliative care in dementia.

**AIM –** This study aims to describe whether residents with dementia in Dutch long-term care facilities die peacefully and to assess which characteristics of the resident, the palliative care provided and the facilities are associated with dying peacefully.

**DESIGN and SETTING –** We analysed existing data from the Dutch End of Life in Dementia study, collected between January 2007 and July 2010 in 34 long-term care facilities in the Netherlands. We used descriptive statistics and Generalized Estimating Equation models.

**RESULTS –** The sample consisted of 233 residents with dementia. Family members indicated that the resident died peacefully in 56% of cases. This percentage ranged from 17% to 80% across facilities. Residents were more likely to die peacefully if they had an optimistic attitude, if family found that there were enough nurses available and if residents died in facilities with a moderate (versus no) perceived influence of religious affiliation on end-of-life decision-making policies.

**CONCLUSIONS –** Only half of the residents with dementia in Dutch long-term care facilities die peacefully, as perceived by relatives. In addition to residents' optimistic attitude, facility characteristics are associated with dying peacefully, which suggests that "the percentage of relatives who indicate that the patient died peacefully" can function as a quality indicator.

## INTRODUCTION

It is a generally accepted belief that people wish to die peacefully. Nevertheless, literature on "dying peacefully" is rather limited. The concept of "dying peacefully" is broad and it is often referred to as "tranquillity",[1] which may be connected to various aspects of emotional and spiritual well-being,[2] such as feeling close to loved ones and feeling deep inner harmony.[3] Furthermore, certain aspects of religiousness, such as regular church attendance and a proxy respondent's estimate of the salience of religion (the importance someone attaches to religion), have been shown to support a sense of peace in the last week of life.[4] Being at peace at the end of life has also been associated with age, with younger patients reporting lower levels of being at peace.[2,4] Thus, so far, most research literature on factors influencing dying peacefully has focussed on personal factors. However, emotional and spiritual well-being, which are related to dying peacefully, may be influenced by the care provided or by the facility in which care is provided. This means that in addition to personal characteristics, characteristics of the palliative care provided and of the care facilities may be related to a peaceful death, suggesting that the percentage of people dying peacefully can function as a quality indicator.[5,6] Quality indicators are explicitly defined, measurable items referring to the outcomes, processes or structure of care.[7,8] Quality indicators describe the quality of the palliative care provided and are increasingly being used to compare quality scores of different care providers in a structured way and to initiate quality improvements, where needed.[5,9-13] In recent years, there has been increasing interest in quality indicators for palliative care.[6,14] One example of a quality indicator referring to an outcome of palliative care is "*the percentage of relatives who indicate that the patient died peacefully*".[5]

Despite the increase in people dying with or from dementia,[15] little is known about whether people with dementia die peacefully; previous publications concerning the subject of a peaceful death mainly focused on non-cognitively impaired patients. In addition, previous studies did not link dying peacefully to the characteristics of the care provided or the care facilities, nor did they examine in that context whether the percentage of people dying peacefully could also function as an indicator of the quality of care. Furthermore, 92.3% of dementia-related deaths in the Netherlands occurred in nursing homes.[16]

Therefore, this article examines:

- Whether residents with dementia in Dutch long-term care facilities die peacefully according to their relatives;
- Which characteristics (a) of the resident, (b) of the palliative care provided and (c) of the specific care facility are associated with dying peacefully.

## METHODS

### Design and setting

We used the dataset of the Dutch End of Life in Dementia (DEOLD) study. This study describes the quality of dying and satisfaction with end-of-life care and decision making from the perspectives of family members and elderly care physicians.[17,18] Long-term care facilities were recruited from all over the Netherlands. The sample was representative as to, for example, the family's evaluation of the general quality of care provided. A total of 19 nursing-home organisations participated, covering a total of 34 long-term care facilities (28 nursing homes and 6 residential homes). Each of these nursing-home organisations employed its own team of qualified elderly care physicians (some physician teams covered more than one facility). In all, 17 participating nursing-home organisations collected data prospectively, meaning that residents were followed from admission to the nursing home until their death or the study conclusion. In addition to this prospective data collection, two organisations collected data retrospectively after death only, to increase the number of reports on decedents while avoiding the complicated logistics involved in prospective studies.[17]

### Data collection

Data were collected between January 2007 and July 2010. In the prospective data collection, elderly care physicians and relatives completed written questionnaires at eight weeks after admission, subsequently every six months and after death (two months after death for relatives, and within two weeks for physicians). In the retrospective data collection, the long-term care facility invited relatives of eligible residents to participate six weeks after death. As in the prospective data collection, physicians completed the questionnaire two weeks after death. The relatives' response rate in the retrospective design (invited after death) was 55% and 58% in the prospective design (invited upon admission).[17] A total of 337 residents died, of whom 248 residents had a complete after-death assessment by a physician and family member. For this study, we selected the 233 residents for whom the family member completed the question about whether their relative died peacefully. This sample comprised 173 decedents (74%) from the prospective data collection, and 60 decedents (26%) from the retrospective data collection.

### Study population

The research subjects were residents who met the following inclusion criteria: (a) had been residing in a psychogeriatric ward or unit in a long-term facility supervised by qualified elderly care physicians, (b) had been diagnosed with dementia by a physician, (c) had been admitted for long-term care, and (d) had a family representative who was able to understand and write Dutch or English.

### Ethical approval

The protocol for the DEOLD study was approved by the Medical Ethics Committee of the VU University Medical Center in Amsterdam. In the prospective design, the long-term care facilities only collected data reported on residents whose families had consented upon admission to taking part. In the retrospective design sending back the questionnaire (around two months after death) was viewed as providing informed consent, and families could object to coded information being transferred to the researchers.

### Variables

The DEOLD study collected data about the resident, about the care process (on an individual resident level) and about the care facility, using questionnaires completed by elderly care physicians and family members. Data were selected from the DEOLD data set if the data concerned variables that were considered to potentially have an influence on dying peacefully. These variables were selected by the authors since they concern palliative and spiritual care, patient-centred care, empathic approach and the structure and organisation of the facility. An overview of the variables used in this study, the respondents and the timing of the questions and the sources is provided in Box 1. The variables consisted of background characteristics, resident characteristics, care characteristics (on an individual level) and facility characteristics.

## Box 1 – Overview of the variables used

| DOMAINS AND VARIABLES | ITEM AND SOURCE | RESPONDENT, TIMING |
|---|---|---|
| **BACKGROUND CHARACTERISTICS** | | |
| - Of the resident: | Age, gender, type of dementia and cause of death. | Physician<br>- after death |
| - Of the family member: | Age and gender. | Family member<br>- after death |
| **RESIDENT CHARACTERISTICS** | | |
| Dying peacefully (outcome) | QOD-LTC item *“he/she appeared to be at peace”*.[19] Original response options: *not at all, a little bit, a moderate amount, quite a bit, completely*. For analyses, we combined “quite a bit” and “completely”. | Family member<br>- after death |
| Symptom burden | Based on SM-EOLD[20,21] *Frequencies of pain, shortness of breath, skin breakdown, calm, depression, fear, anxiety, agitation, resistiveness to care*. For analyses, we calculated a total score after exclusion of the item “calm” (the only positive item, other items refer to symptoms). | Physician<br>- after death |
| Importance of faith or spirituality | CASCADE item *“importance of faith”*.[22] | Family member<br>- baseline study |
| Optimistic attitude | Developed for purpose of the DEOLD,[17,18] *Did your family member generally have an optimistic or a more pessimistic attitude? Response options: “pessimistic; neither pessimistic, nor optimistic; optimistic”*. | Family member<br>- baseline study |
| Advanced dementia | Developed for purpose of the DEOLD,[17,18] *Advanced dementia was defined using two instruments: Cognitive Performance Scale (CPS) 5 or 6* [23] *and Global Deterioration Scale (GDS) 7*.[24] | Physician<br>- after death |
| Relation to family member | For analyses, a pre-structured listing of 7 response options was combined into: *“spouse, son/daughter, other*”. | Family<br>- after death |
| **CARE CHARACTERISTICS** | | |
| Adequate personal attention | Developed for purpose of the DEOLD,[17,18] *I feel that my relative/loved one receives adequate personal attention.* | Family<br>- after death |
| Adequate personal care | Developed for purpose of the DEOLD,[17,18] *I feel that my relative/loved one receives good personal care (washing, brushing teeth, etc.).* | Family<br>- after death |
| Always treated with respect | TIME item “*How often was (he/she) treated with respect by those who were taking care of (him/her)”*.[25,26] For analyses, response options were dichotomized into “*always*”= always; *“usually, sometimes, or never”*= not always. | Family<br>- after death |
| Always treated with kindness | TIME item “*How often was (he/she) treated with kindness by those who were taking care of (him/her)”*.[25,26] For analyses, response options were dichotomized into: “*always*”= always; *“usually, sometimes, or never”*= not always. | Family<br>- after death |
| Care goal priority for palliative or symptomatic care[*] | *Which of the following care goals had priority on the day the resident died?*[27] Original response options: *curative care goal, maintaining or improving function, palliative care goal, symptomatic care goal*[*]. For analyses, options were dichotomized into: *“not having a palliative or symptomatic care goal”; “having a palliative or symptomatic care goal”.* | Physician<br>- after death |

## Box 1 – continued -

| DOMAINS AND VARIABLES | ITEM AND SOURCE | RESPONDENT, TIMING |
|---|---|---|
| Spiritual care provided at the end of life | Developed for purpose of the DEOLD,[17,18] *Did the resident receive spiritual care (pastoral care involving the last sacraments or another last rite) shortly before death?* | Physician<br>- after death |
| Resident lived in a small-scale living facility (6-8 residents[28,29]) | *Was the resident living in a small-scale living facility?* | Physician<br>- conclusion study |
| **FACILITY CHARACTERISTICS** | | |
| Number of psychosocial interventions provided (incl. the last phase of life) | Developed for purpose of the DEOLD,[17,18] *Which psychosocial interventions are provided to residents with dementia including in the last phase of life?*<br>Pre-structured listing from which the number of relevant activities for the end-of-life was calculated. | Physician<br>- conclusion study |
| Religious affiliation is reflected in end-of-life decision making policies | Developed for purpose of the DEOLD,[17,18] *To what degree do you feel the religious affiliation of your nursing home is reflected in policy regarding end-of-life decisions?* | Physician<br>- midway study |
| Enough nurses available | Developed for purpose of the DEOLD,[17,18] *Do you feel that enough nurses are available on the psychogeriatric wards at this moment?* For analyses, response options were dichotomized into: *"yes, more than enough"; "yes, just enough"*= enough staff; *"no, not enough"*= not enough staff. | Physician<br>- conclusion study |
| Enough physicians available | Developed for purpose of the DEOLD,[17,18] *Do you feel that enough physicians are available on the psychogeriatric wards at this moment?* For analyses, response options were dichotomized into: *"yes, more than enough"; "yes, just enough"*= enough staff; *"no, not enough"*= not enough staff. | Physician<br>- conclusion study |
| Quality of the nurses is adequate | Developed for purpose of the DEOLD,[17,18] *Do you feel the quality of nurses is adequate?* | Physician<br>- conclusion study |
| Family finds enough nurses available | Developed for purpose of the DEOLD,[17,18] *Do you feel that enough nurses were available in the last week of life?* For analyses, response options were dichotomized into *"yes, more than enough"; "yes, just enough"*= enough staff; *"no, not enough"*= not enough staff. | Family<br>- after death |

QOD-LTC= Quality of Dying in Long-term Care;[19] SM-EOLD= Symptom Management at the End of Life with Dementia;[20,21] CASCADE= Choices, Attitudes, and Strategies for Care of Advanced Dementia at the End-of-Life;[22] DEOLD= Dutch End of Life in Dementia;[17,18] TIME= Toolkit of Instruments to Measure End-of-life care[25,26]

* The following definitions were used:
Palliative care goal: *A care goal aimed primarily at safeguarding optimal well-being and an acceptable quality of life of the patient with dementia. This goal is achieved by: treatment of other complaints, co-morbidity, symptoms and complications resulting from the dementia. Extending life as a potential side effect of this treatment is not contraindicated - or is even part of the care goal.*
Symptomatic care goal: *A care goal aimed primarily at safeguarding optimal well-being and an acceptable quality of life of the patient with dementia. This goal is achieved by: treatment of other complaints, co-morbidity, symptoms and complications resulting from the dementia. A life-extending side-effect as a result of medical treatment aimed at this goal is undesirable.*

### Data analysis

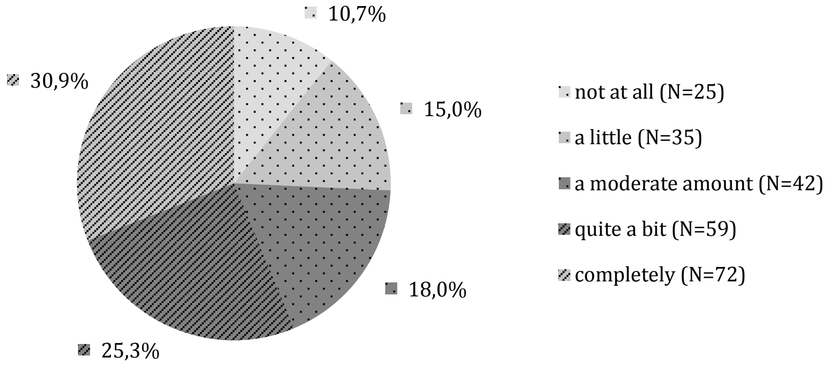
Statistical analyses were performed using IBM SPSS Statistics software Version 20.0 (IBM Corp., 2011, Armonk, NY). First, frequencies and descriptive statistics were calculated for the study population, the outcome variable “dying peacefully” and the potentially associated characteristics -the care characteristics and facility characteristics shown in Box 1. Second, missing data were imputed using multiple imputations,[30] and 10 imputed datasets were generated with the Predictive Mean Matching method. Third, linear regression analyses were performed using the Generalized Estimating Equations (GEE) method to examine the association between dying peacefully and the potentially associated characteristics for each imputed dataset. Resident characteristics were used to adjust for case-mix differences between facilities. The GEE technique was used to account for correlated observations that emerge because of residents’ clustering in long-term care facilities. We used an independence matrix as the working correlation matrix. Finally, the results from all the imputed data sets were pooled into a unique set of parameters and standard errors. We tested the model both with and without “symptom burden” as a one of the adjustment factors, since this item may itself be influenced by the quality of care provided.

## RESULTS

### Dying peacefully

Family members thought that the resident had died peacefully in 56% of cases (“completely” or “quite a bit” at peace in the last month of life) (Figure 1). On the other hand, 11% of family members said that their beloved one did not die peacefully at all.

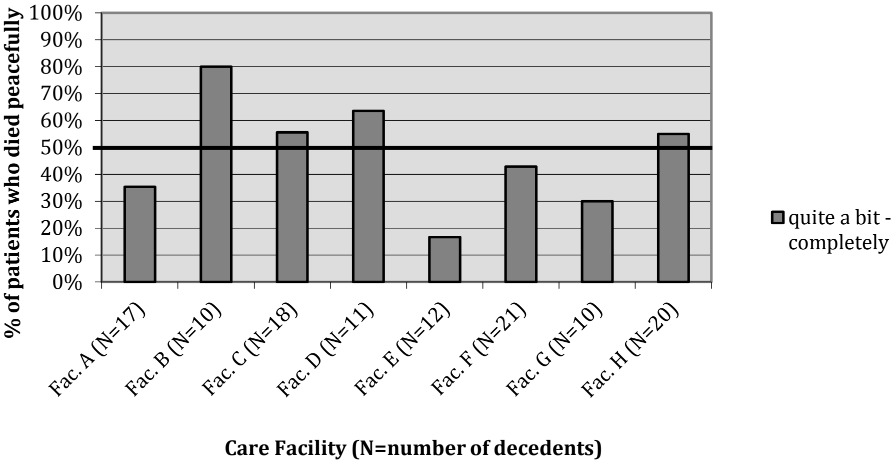
**Figure 1 – Percentage dying peacefully in residents with dementia in long-term care facilities (N=233)**



“Not at all”, “a little” and “a moderate amount” were seen as not dying peacefully.
“Quite a bit” and “completely” were seen as dying peacefully.

We calculated the percentage of residents dying peacefully per facility for the eight facilities that had ten or more decedents. The percentage of residents who died peacefully varied between 17% and 80%, with most facilities having a percentage between 30% and 64% (Figure 2).

**Figure 2 – Percentage of residents who died peacefully per facility**[*]



[*] Facilities (Fac.) are only shown in this figure, if they had ten or more decedents.

### Resident characteristics and their association with dying peacefully

The majority of the 233 decedents were female (67%); the mean age at death was 85.7 years (Table 1). Less than half of the residents died with advanced dementia (46%), whereas dementia was mentioned as a direct or contributing cause of death in 87% of cases (Table 1). The majority of family members considered their resident as being neutral to optimistic (82%). Faith or spirituality was considered to be somewhat to very important to 71% of the residents (Table 1). The minimum reported score for the symptom burden was 0.5, the maximum was 40 and the mean symptom burden was 24.7 (standard deviation (SD)=8.4) (Table 1). The majority of family members (N=233) were female (60%); the mean age was 60.0 years. Most family members were children of the residents (65%) and 17% were spouses.

Resident characteristics were used as adjustment factors. In the multivariable analysis, having an optimistic attitude was found to be associated with dying peacefully in a stepwise fashion (B for “neither optimistic nor pessimistic attitude” versus “pessimistic attitude”=0.40, p=0.04; B for “optimistic attitude” versus “pessimistic attitude”=0.53, p<0.001). This was the only resident characteristic associated with dying peacefully. We noted no differences between the models with symptom burden as one of the adjustment factors and those without symptom burden.

## Table 1 – Characteristics of the residents (N=233)

| | **RESIDENTS %** |
|---|---|
| **Female sex** | 66.5 |
| **Age at death (mean (SD))*** | 85.7 (7.2) |
| **Type of dementia**† | |
| Alzheimer | 41.0 |
| Vascular dementia | 27.3 |
| Lewy Body dementia | 5.7 |
| Alzheimer's and vascular dementia | 16.7 |
| All other combinations | 9.3 |
| **Advanced dementia**‡ | 46.4 |
| **(Contributing) cause of death**§ | |
| Dementia | 87.1 |
| Cardiovascular disease | 43.8 |
| Dehydration | 42.9 |
| Respiratory infection | 24.6 |
| Other infections | 11.6 |
| Cachexia | 23.2 |
| Malignancy | 8.9 |
| **Importance of faith or spirituality**\|\| | |
| Not at all important | 28.7 |
| Somewhat important | 34.1 |
| Very important | 37.2 |
| **Optimistic attitude**¶ | |
| Pessimistic | 17.8 |
| Neither pessimistic, nor optimistic | 42.6 |
| Optimistic | 39.6 |
| **Symptom burden (mean (SD))** ** | 24.7 (8.4) |

SD= standard deviation
* 4 missing values.
† 6 missing values.
‡ Advanced dementia was defined as Global Deterioration Scale stage 7 and a Cognitive Performance Scale of 5 or 6; 9 missing values.
§ We listed all causes of death with a minimum of 5%; "cause of death" refers to all causes of death which were listed anywhere on the death certificate, this includes both the direct cause of death and contributing causes of death; 9 missing values.
|| 10 missing values.
¶ 3 missing values.
**The possible scores range from 0 to 40 with a higher score indicating better symptom control; 20 missing values.

### Characteristics of the care provided and the facilities, and their association with dying peacefully

Table 2 shows the frequencies of the characteristics potentially associated with dying peacefully: the characteristics of the care provided and the structural characteristics of the long-term care facilities.

## Table 2 – Characteristics of the care provided and of the long-term care facilities

| | **RESIDENTS (N=233)**<br>**N (%)** |
|---|---|
| **CARE CHARACTERISTICS** | |
| **Adequate personal attention**[*,†] | |
| Disagree | 35 (15.3) |
| Agree | 110 (48.0) |
| Strongly agree | 84 (36.7) |
| **Adequate personal care (e.g. washing, brushing teeth)** [†,‡] | |
| Disagree | 32 (14.0) |
| Agree | 118 (51.8) |
| Strongly agree | 78 (34.2) |
| **Always treated with respect** [†,§] | 191 (83.4) |
| **Always treated with kindness**[||,†] | 189 (83.3) |
| **Care goal priority for palliative or symptomatic care**[¶,**] | 203 (89.8) |
| **Spiritual care provided at the end of life**[**,††] | 60 (27.3) |
| **Resident lived in a small-scale living facility**[**,‡‡] | 63 (27.2) |
| **FACILITY CHARACTERISTICS** | **N (%)** |
| **Number of psychosocial interventions provided (including the last phase of life)**[**,§§] | |
| No interventions | 27 (11.7) |
| 1 intervention | 0 (0.0) |
| 2 interventions | 19 (8.2) |
| 3 interventions | 114 (49.4) |
| 4 interventions | 71 (30.7) |
| 5 interventions | 0 (0.0) |
| **Religious affiliation is reflected in end-of-life decision making policies**[**,||||] | |
| No influence or no religious affiliation | 131 (60.1) |
| Moderate influence | 64 (29.4) |
| Strong influence | 23 (10.6) |
| **Enough nurses available**[**,¶¶] | 103 (54.8) |
| **Enough physicians available**[**,¶¶] | 131 (69.7) |
| **Quality of nurses is adequate**[**,¶¶] | |
| Inadequate | 42 (22.3) |
| Just adequate | 86 (45.7) |
| More than adequate | 60 (31.9) |
| **Family finds enough nurses available**[†,***] | 196 (86.7) |

[*] 4 missing values.

[†] Answered by the family member.

[‡] 5 missing values.

[§] 4 missing values.

[||] 6 missing values.

[¶] 7 missing values.

[**] Answered by the physician.

[††] Shortly before death, pastoral care was provided involving the last sacraments, or another last rite; 13 missing values.

[‡‡] In small-scale living facilities six to eight residents live together in a homelike environment, where they take part in normal daily activities;[28,29] 1 missing value.

[§§] These psychosocial interventions had to be chosen from a pre-structured listing, and could only be chosen if they were offered to residents with dementia including the last phase of life; 2 missing values.

[||||] 15 missing values.

[¶¶] 45 missing values.

[***] 7 missing values.

After correcting for resident characteristics in the univariable analysis, dying peacefully is positively associated with the following care characteristics: adequate personal attention (in a stepwise fashion, Table 3), adequate personal care (B for "strongly agree"=0.44, p=0.048), always treated with respect (B=0.42, p=0.017) and always treated with kindness (B=0.54, p=0.002) (Table 3). Regarding characteristics of the long-term care facilities, when family members found that enough nurses were present, this was positively associated with the families' perception that the resident died peacefully (B=0.55, p<0.001, Table 3).

In the multivariable analysis, none of the care characteristics was significantly associated with dying peacefully. Two facility characteristics were positively associated with dying more peacefully: a moderate influence of religious affiliation on the facility's end-of-life decision- making policies (B=0.41, p=0.03) and family members' opinion that there were enough nurses available (B=0.44, p=0.005).

### Table 3 – Univariable and multivariable models dying peacefully in long-term care facility residents with dementia (N=233)

| CHARACTERISTICS | UNIVARIABLE B (95% CI) | MULTIVARIABLE B (95% CI) |
|---|---|---|
| **CARE CHARACTERISTICS** | | |
| **Adequate personal attention** | | |
| Disagree | reference | reference |
| Agree | **0.42 (0.1 ; 0.7)**$^{**}$ | 0.20 (-0.1 ; 0.6) |
| Strongly agree | **0.56 (0.3 ; 0.9)**$^{*}$ | 0.22 (-0.2 ; 0.7) |
| **Adequate personal care** | | |
| Disagree | reference | reference |
| Agree | 0.24 (-0.1 ; 0.6) | -0.20 (-0.6 ; 0.2) |
| Strongly agree | **0.44 (0.0 ; 0.9)**$^{*}$ | -0.08 (-0.7 ; 0.5) |
| **Always treated with respect** | **0.42 (0.1 ; 0.8)**$^{*}$ | 0.07 (-0.3 ; 0.5) |
| **Always treated with kindness** | **0.54 (0.2 ; 0.9)**$^{*}$ | 0.30 (-0.2 ; 0.8) |
| **No care goal priority for palliative/symptomatic care** | -0.02 (-0.5 ; 0.4) | 0.13 (-0.3 ; 0.5) |
| **Spiritual care provided at the end of life**† | 0.05 (-0.3 ; 0.4) | 0.03 (-0.3 ; 0.4) |
| **Resident lived in a small-scale living facility** | 0.22 (-0.1 ; 0.5) | 0.20 (-0.2 ; 0.6) |
| **FACILITY CHARACTERISTICS** | | |
| **Number of psychosocial interventions provided (including the last phase of life)**‡ | 0.04 (-0.1 ; 0.2) | 0.04 (-0.1 ; 0.2) |
| **Religious affiliation is reflected in end-of-life decision making policies** | reference | reference |
| No influence or no religious affiliation | 0.24 (-0.2 ; 0.6) | **0.41 (0.1 ; 0.8)**$^{*}$ |
| Moderate influence | 0.01 (-0.3 ; 0.5) | 0.07 (-0.3 ; 0.5) |
| Strong influence | | |
| **Enough nurses available** | 0.10 (-0.3 ; 0.5) | -0.05 (-0.5 ; 0.4) |
| **Enough physicians available** | 0.19 (-0.2 ; 0.5) | 0.12 (-0.4 ; 0.7) |
| **Quality of nurses is adequate** | | |
| Inadequate | reference | reference |
| Just adequate | 0.13 (-0.2 ; 0.5) | 0.02 (-0.5 ; 0.6) |
| More than adequate | 0.23 (-0.2 ; 0.7) | 0.02 (-0.6 ; 0.7) |
| **Family finds enough nurses available** | **0.55 (0.3 ; 0.8)**$^{**}$ | **0.44 (0.1 ; 0.7)**$^{*}$ |

CI= confidence interval. B regression coefficients marked in bold, with * are significant $p<0.05$, B regression coefficients marked in bold, with ** are significant $p<0.001$.

The following characteristics of the residents were used in all analyses as adjusting factors: age of the resident, gender of the resident, symptom burden of the resident, importance of faith or spirituality, optimistic attitude of the resident, advanced dementia and relation to the family member.

† Shortly before death, pastoral care was provided involving the last sacraments, or another last rite.

‡ Psychosocial interventions were selected from a pre-structured listing indicating those offered to residents with dementia including the last phase of life.

## DISCUSSION

Only 56% of residents (N=233) in Dutch long-term care facilities died peacefully according to their relatives. This percentage differs between the different long-term care facilities, ranging from 17% to 80%, which means that the quality indicator “the percentage of relatives who indicate that the patient died peacefully” could reveal quality differences between different facilities. Most facilities had a percentage between 30% and 64%.

Residents having a neutral (neither optimistic, nor pessimistic) or optimistic attitude were more likely to die peacefully than people with a pessimistic attitude. Surprisingly, none of the selected care characteristics we had expected to have an association with dying peacefully had significant associations with dying peacefully in the multivariable model. Adequate personal attention, always being treated with respect and always being treated with kindness were associated with dying peacefully in the univariable model (correcting for resident characteristics), which suggests that these care characteristics are dependent on other care and facility characteristics. Two facility characteristics were associated with dying peacefully: residents were more likely to die peacefully in a facility where elderly care physicians perceived a moderate influence of religious affiliation on end-of-life decision-making policies and in a facility where their relatives found that there were enough nurses available.

Our results show that specific facility characteristics relate to dying peacefully, in addition to the influence of the residents’ personal characteristics. This suggests that specific facility characteristics do indeed matter and make a difference in the quality of care provided. Although we can never fully exclude other potential aspects that play a role in the revealed differences of dying peacefully between different facilities, it is assumable that these differences are indicators of differences in the quality of care provided, since we saw that certain facility and care characteristics are related to differences in the percentage of residents dying peacefully.

To our knowledge, there are no previous studies that describe characteristics of the care provided or the care facilities that are associated with dying peacefully. Therefore, we are not able to draw from or compare with existing evidence. We only explored one quality indicator here and although this single quality indicator highlights an important outcome of the quality of palliative care, it highlights only one aspect of care. Therefore, it should preferably be used in combination with other quality indicators to give a broader perspective on the palliative care provided.

We did not find an association of dying peacefully with symptom burden. The inclusion or exclusion of symptom burden in the model did not affect other associations. We presumed that this item could itself be influenced by the quality of care provided, but it had no effect on revealing other associated characteristics. This suggests that family members perceive dying peacefully with dementia as a concept that is distinct from symptom burden. Measuring dying peacefully and symptom burden in this patient population by using family members as proxies covers two different outcomes of palliative care, each of which reflects a different aspect of the quality of palliative care provided.

### Limitations and strengths

This study is, as far as we know, the first to describe dying peacefully in a dementia population. We considered it a benefit to use the existing DEOLD data set, since we were able to evaluate dying peacefully and its potential as a quality indicator without having to collect new data. The questionnaire item in the DEOLD study referred to whether the resident was "at peace" in the last month of life and was considered sufficiently close to "dying peacefully" as phrased in the original quality indicator developed by Claessen *et al.*[5] It was an advantage that we could use the existing data of a validated instrument to measure dying peacefully in a population with dementia.

However, the original limitations are also present in this study. The DEOLD study comprised both a prospective and retrospective data collection, but this did not affect the associations we found. For the facility characteristics, we had to rely on the opinion of the coordinating elderly care physician, while for the outcome "dying peacefully" we relied on the observations of the family members. However, we have no data on what kind of signs or expressions of the resident families use to discern whether a patient died peacefully. We recommend future research to shed light on the signs or expressions by the patient that explain families' judgment of dying peacefully. Since we did not have high number of decedents per facility, we were not able to perform a case-mix adjustment, that is, correcting the percentage of residents dying peacefully per facility and we recommend taking this into account in future research.

## CONCLUSION

Our finding that dying peacefully is related to care facility characteristics highlights its potential as a quality indicator for measuring the quality of palliative care provided. However, before using this quality indicator in practice, we recommend research be done to evaluate the discriminative power of the indicator (whether it can indeed reveal differences between care facilities, taking into account the patient case mix), and to test it in other settings.

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## REFERENCES

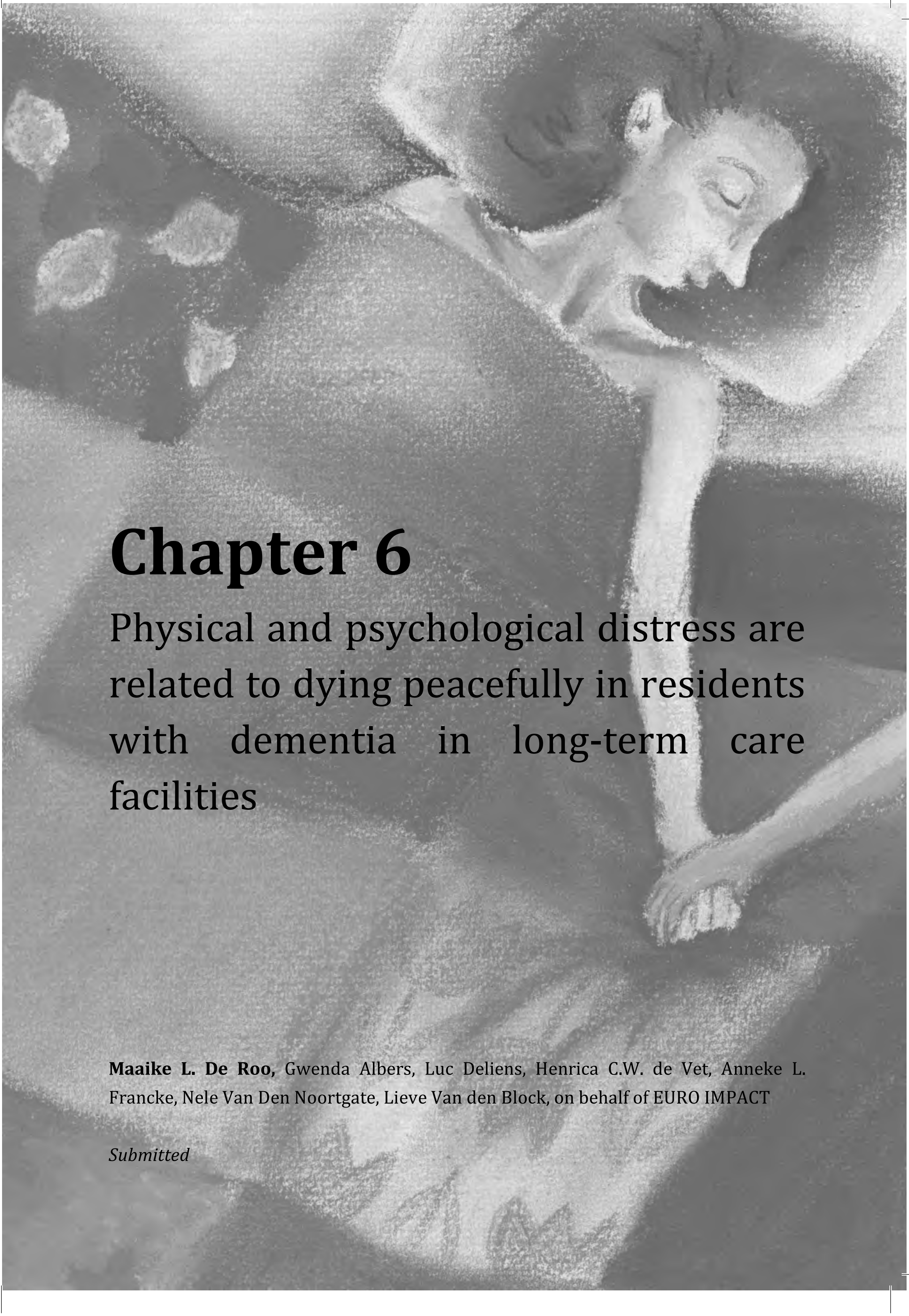
1. Roberts KT, Aspy CB. Development of the Serenity Scale. J Nurs Meas 1993;1(2):145-164.
2. Steinhauser KE, Voils CI, Clipp EC, Bosworth HB, Christakis NA, Tulsky JA. "Are you at peace?": one item to probe spiritual concerns at the end of life. Arch Intern Med 2006;166(1):101-105.
3. Ray A, Block SD, Friedlander RJ, Zhang B, Maciejewski PK, Prigerson HG. Peaceful awareness in patients with advanced cancer. J Palliat Med 2006;9(6):1359-1368.
4. Braam AW, Klinkenberg M, Deeg DJH. Religiousness and mood in the last week of life: an explorative approach based on after-death proxy interviews. J Palliat Med 2011;14(1):31-37.

5. Claessen SJJ, Francke AL, Belarbi HE, Pasman HR, van der Putten MJA, Deliens L. 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.
6. De Roo ML, Leemans K, Claessen SJJ, Cohen J, Pasman HR, Deliens L, Francke AL. Quality Indicators for Palliative Care: Update of a Systematic Review. J Pain Symptom Manage 2013;46(4):556-572.
7. Campbell SM, Braspenning J, Hutchinson A, Marshall MN. Research methods used in developing and applying quality indicators in primary care. BMJ 2003;326(7393):816-819.
8. Donabedian A. The quality of care. How can it be assessed? JAMA 1988;260(12):1743-1748.
9. Campbell SM, Roland MO, Buetow SA. Defining quality of care. Soc Sci Med 2000;51(11):1611-1625.
10. Bowman KW, Martin DK, Singer PA. Quality end-of-life care. J Eval Clin Pract 2000;6(1):51-61.
11. Rosenfeld K, Wenger NS. Measuring quality in end-of-life care. Clin Geriatr Med 2000;16(2):387-400.
12. Davies E, Higginson IJ, eds. The solid facts: Palliative care. Geneva: World Health Organisation, 2004.
13. Ferrell B, Connor SR, Cordes A, Dahlin CM, Fine PG, Hutton N, Leenay M, Lentz J, Person JL, Meier DE, Zuroski K. The national agenda for quality palliative care: the National Consensus Project and the National Quality Forum. J Pain Symptom Manage 2007;33(6):737-744.
14. Pasman HR, Brandt HE, Deliens L, Francke AL. Quality indicators for palliative care: a systematic review. J Pain Symptom Manage 2009;38(1):145-156.
15. World Health Organisation (WHO). Dementia: a public health priority. Geneva: WHO, 2012. Available at www.who.int/mental_health/publications/dementia_report_2012/en/index.html. Accessed 19th December 2014.
16. Houttekier D, Cohen J, Bilsen J, Addington-Hall J, Onwuteaka-Philipsen BD, Deliens L. Place of death of older persons with dementia. A study in five European countries. J Am Geriatr Soc 2010;58(4):751-756.
17. van der Steen JT, Ribbe MW, Deliens L, Gutschow G, Onwuteaka-Philipsen BD. Retrospective and Prospective Data Collection Compared in the Dutch End of Life in Dementia (DEOLD) Study. Alzheimer Dis Assoc Disord 2014;28(1):88-94.
18. van der Steen JT, Deliens L, Ribbe MW, Onwuteaka-Philipsen BD. Selection bias in family reports on end of life with dementia in nursing homes. J Palliat Med 2012;15(12):1292-1296.
19. Munn JC, Zimmerman S, Hanson LC, Williams CS, Sloane PD, Clipp EC, Tulsky JA, Steinhauser KE. Measuring the quality of dying in long-term care. J Am Geriatr Soc 2007;55(9):1371-1379.
20. Volicer L, Hurley AC, Blasi ZV. Characteristics of dementia end-of-life care across care settings. Am J Hosp Palliat Care 2003;20(3):191-200.
21. Volicer L, Hurley AC, Blasi ZV. Scales for evaluation of End-of-Life Care in Dementia. Alzheimer Dis Assoc Disord 2001;15(4):194-200.
22. Mitchell SL, Kiely DK, Jones RN, Prigerson H, Volicer L, Teno JM. Advanced dementia research in the nursing home: the CASCADE study. Alzheimer Dis Assoc Disord 2006;20(3):166-175.
23. Morris JN, Fries BE, Mehr DR, Hawes C, Phillips C, Mor V, Lipsitz LA. MDS Cognitive Performance Scale. J Gerontol 1994;49(4):M174-M182.
24. Reisberg B, Ferris SH, de Leon MJ, Crook T. The Global Deterioration Scale for assessment of primary degenerative dementia. Am J Psychiatry 1982;139(9):1136-1139.
25. Teno J. TIME: Toolkit of Instruments to Measure End-of-life care. 2004. Available from: http://www.chcr.brown.edu/pcoc/linkstoinstrumhtm.htm. Accessed 19th December 2014.
26. Teno JM, Clarridge BR, Casey V, Welch LC, Wetle T, Shield R, Mor V. Family perspectives on end-of-life care at the last place of care. JAMA 2004;291(1):88-93.
27. Hertogh C. Advance care planning and palliative care in the dementia: a view from the Netherlands. In: Hughes C, Lloyd-Williams M, Sachs GA, eds. Supportive Care for the Person with Dementia. New York: Oxford University Press Inc., 2010: 271-280.

28. Verbeek H, van Rossum E, Zwakhalen SMG, Kempen GIJM, Hamers JPH. Small, homelike care environments for older people with dementia: a literature review. Int Psychogeriatr 2009;21(2):252-264.

29. Verbeek H, Zwakhalen SMG, van Rossum E, Kempen GIJM, Hamers JPH. Small-scale, homelike facilities in dementia care: a process evaluation into the experiences of family caregivers and nursing staff. Int J Nurs Stud 2012;49(1):21-29.

30. van Buuren S. Flexible Imputation of Missing Data. Boca Raton, FL: Chapman & Hall/CRC Press, 2012.



# Chapter 6

## Physical and psychological distress are related to dying peacefully in residents with dementia in long-term care facilities

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*Submitted*

## ABSTRACT

**CONTEXT –** Although dying peacefully is considered an important outcome of high-quality palliative care, large-scale quantitative research on dying peacefully and the factors associated with a peaceful death is lacking.

**OBJECTIVES –** To give insight into how many residents with dementia in long-term care facilities die peacefully, according to their relatives, and whether that assessment is correlated with observed physical and psychological distress.

**METHODS –** A retrospective cross-sectional study of deceased nursing home residents in a representative sample of long-term care facilities in Flanders, Belgium (in 2010). Structured post-mortem questionnaires were completed by a relative of the resident. The nurse most involved in the resident's care, and the facility administrator provided additional data. Spearman correlation coefficients gave the correlations between physical and psychological distress (as measured using SM-EOLD and CAD-EOLD) and dying peacefully (as measured using QOD-LTC).

**RESULTS –** The sample consisted of 92 relatives of deceased residents with dementia. In 54% of cases, relatives indicated that the resident died peacefully. Weak to moderate correlations (0.22-0.57) were found between dying peacefully and physical distress in the last week of life. Regarding psychological distress, weak to moderate correlations were found for both the last week (0.33-0.44) and last month of life (0.28-0.47).

**CONCLUSIONS –** Only half of the residents with dementia died peacefully as judged by their relatives. Relatives' assessment of whether death was peaceful is related to both physical and psychological distress. Further qualitative research is recommended to gain more in-depth insights into the aspects on which aspects relatives base their judgment of dying peacefully.

## INTRODUCTION

It is a widely accepted assumption that people wish to die peacefully. In addition, dying peacefully is considered an important outcome of high-quality palliative care.[1] However, large-scale quantitative research about how peacefully people die or what factors are associated with a peaceful death is lacking. The little research there has been up to now has focused predominantly on terminally ill patients who were not cognitively impaired. Research by Steinhauser *et al.*, for instance, showed that terminally ill patients with cancer or AIDS, recently bereaved family members, and health-care professionals considered “having come to peace” or “being at peace” attributes of a “good death”.[2,3] In addition, Steinhauser *et al.* found that being at peace was strongly positively correlated with emotional and spiritual well-being.[3,4] Ray *et al.* demonstrated that advanced cancer patients who felt at peace had less psychological distress and had a higher overall quality of death as reported by their caretakers.[5] Peacefulness was found to be significantly associated with spirituality, but much of the variance remained unexplained.[5]

In ageing societies, the number of people suffering from dementia is increasing, as is the number of people dying with dementia.[6] Since people with dementia very often reside and die in long-term care facilities,[7,8] it is important to get a more in-depth understanding of what factors contribute to a peaceful death in people with dementia in these facilities. There is only one recent study on this subject, which revealed that only half of the residents (56%) with dementia in long-term care facilities in the Netherlands (N=233) died peacefully according to their relatives.[9] Residents were not only more likely to die peacefully if they had an optimistic attitude, but also if relatives found that there were enough nurses available and if residents died in facilities with a moderate perceived influence of religious affiliation on end-of-life decision-making policies (as opposed to no influence).[9]

Dying peacefully as perceived by relatives is a highly subjective outcome;[1] still, relatives can be considered as an appropriate “proxy” for patients and hence taking their perspective into account is essential. Moreover, if relatives perceive death as not peaceful, this can hamper their bereavement process and can affect their health and well-being.[5] Therefore, getting insights into how relatives judge whether the death was peaceful is crucial. More specifically, we are interested in whether the physical and psychological suffering of the resident is associated with dying peacefully as judged by relatives. We expect that residents are perceived to die less peacefully when their physical and psychological distress is higher.

This study aims to explore:

- How many residents with dementia in long-term care facilities in Flanders, Belgium, die peacefully according to their relatives.
- Whether the judgment of a peaceful death relates to physical and psychological distress in residents with dementia in long-term care facilities in Flanders, Belgium.

## METHODS

### Study design and setting

The Dying Well with Dementia study[10-13] is a retrospective cross-sectional study in a representative sample of long-term care facilities in Flanders. Flanders is the northern Dutch-speaking part of Belgium where the majority of the population live (60%). In Belgium, the majority of older people with dementia (65.9%) die in long-term care facilities.[8] The care of individual residents is managed by their own general practitioner (GP). Nursing care is provided by skilled nurses who are available 24 hours a day.

A random sample was taken of 69 Flemish long-term care facilities, stratified for region, size, and ownership (public, private/non-profit, private/profit), as these factors have been found to be related to end-of-life care quality in long-term care facilities in previous research.[14,15] A detailed description of the study design can be found elsewhere.[11-13]

The Medical Ethical Committee of UZ Brussel (University Hospital of Brussels) approved the study protocol. Patient anonymity and GP's confidentiality were maintained throughout the study.

### Study population

The administrators of the long-term care facilities in the sample made a selection from all the residents who died with dementia between May and October 2010, selecting residents meeting the following criteria used by the Belgian health-insurance system: either the person has a category C dementia, i.e. was "completely care dependent or in need of help for bathing, dressing, eating, toileting, continence, and transferring, plus showing signs of disorientation in time and space", or was "having a problem with orientation in time and space on an almost daily basis". This first broad selection minimized the risk of missing eligible residents with dementia but risked including residents who were not cognitively impaired. Therefore, GPs and nurses of residents fulfilling these criteria were sent questionnaires in which additional eligibility criteria were assessed. These additional eligibility criteria required an indication from the GP or nurse that the resident "had dementia" or "was diagnosed with dementia." In this study, we only included the residents in the analyses whose relative had completed the question concerning dying peacefully.

**Data collection**

Different structured questionnaires were completed by the nurse most involved in care for the resident, a close relative (family member or friend) of the resident, and the administrator of the long-term care facility. The nurses and administrators received a questionnaire no later than three months after the resident's death. Non-respondents received a reminder after three weeks, mediated (in the case of the nurses) by the administrator of the long-term care facility to guarantee anonymity. Relatives received the questionnaire no earlier than two weeks and no later than three months after the resident's death; non-responding relatives also received a reminder.

**Measurements**

Dying peacefully was surveyed in the relatives' questionnaire using the following question, which was originally an item of the Quality of Dying in Long Term Care instrument (QoD-LTC) validated in Dutch:[16,17] "*I would like you to think back over the last month of [RESIDENT'S] life. Here are some statements that have been considered important during the dying process. Please tell me how true this statement is for [RESIDENT]: "[RESIDENT] appeared to be at peace"."* The response options included: *"not at all", "a little bit", "a moderate amount", "quite a bit" and "completely*".

The relatives questionnaire also included the Symptom Management at the End of Life with Dementia scale (SM-EOLD) to explore the frequency of distressing physical and psychological symptoms in the last month of life. The SM-EOLD consists of nine items (three physical and six psychological) with a response scale ranging from 0 to 5, with higher scores indicating lower symptom frequency.[18] In addition, the relatives' questionnaire included the Comfort Assessment in Dying at the End of Life with Dementia scale (CAD-EOLD)[18] consisting of fourteen items that were scored on a scale ranging from 1 to 3, with higher scores indicating more comfort during the last week of life. The CAD-EOLD has four subscales: "physical distress", "dying symptoms", "emotional distress" and "well-being". Both the SM-EOLD and CAD-EOLD were validated in Dutch.[16]

In the current study, we use the three physical symptoms of the SM-EOLD scale, and the "physical distress" and "dying symptoms" subscales of the CAD-EOLD instrument to evaluate physical distress. For psychological distress, we use the six SM-EOLD items concerning psychological symptoms in the last month of life, and the "emotional distress" and "well-being" subscales of the CAD-EOLD instrument. Besides rating these scales, relatives were also asked to state their gender, age, and relation to the resident. The nurses' questionnaire surveyed the functional and cognitive status one month before death with the help of the following validated instruments: the Global Deterioration Scale (GDS),[19] classifying dementia into seven stages based on deficits in cognition and function,[7] and the Cognitive Performance Scale (CPS).[7,20] Advanced dementia was defined as Global Deterioration Scale stage 7 and a Cognitive Performance Scale of 5 or 6.[7] The administrators' questionnaire included questions about the resident's gender, age and date of admission to the long-term care facility.

**Data analysis**

Statistical analyses were performed using IBM SPSS Statistics software Version 20.0 (IBM Corp., 2011, Armonk, NY). Frequencies and descriptive statistics were calculated for the deceased residents with dementia and the relatives who rated the symptoms. On all the EOLD scales, item scores were reversed if the items reflected negative conditions in order to enhance the interpretability: higher scores indicate better symptom control in the last month of life and more comfort in the last week of life. We used Spearman correlation coefficients to explore whether the validated (sub)scales[16,21] concerning the residents' physical and psychological distress were related to dying peacefully in the residents in this sample. Correlation coefficients between 0.7 and 0.9 are considered to indicate strong correlation, coefficients between 0.4 and 0.6 to indicate moderate correlation, and coefficients between 0.1 and 0.3 to indicate weak correlation.[22]

Since we presumed that the psychological subscale of the SM-EOLD scale containing the item "calm" would have high correlations with dying peacefully, we performed the analysis both with and without the "calm" item.

## RESULTS

### Description of the sample

As Table 1 shows, 65% (N=57) of the relatives who filled out the questionnaire were female; the mean age was 60.5 years. Of these relatives, 69% (N=63) were the resident's offspring, 8% (N=7) the spouse. Our study sample consisted of 92 residents with dementia, of whom 59% (N=51) were female; the mean age was 87.5 years and half of them (49%, N=45) had advanced dementia. The median length of stay in a long-term care facility was two years (Table 1).

Regarding physical distress, the lowest symptom control and comfort levels were reported for pain in the last month of life (mean SM-EOLD score 1.8) and difficulty in swallowing in the last week of life (mean CAD-EOLD score 1.8). The highest comfort levels were reported for skin breakdown in the last month of life (mean SM-EOLD score 3.9) and shortness of breath in the last week of life (mean CAD-EOLD score 2.2). As regards psychological distress, the lowest comfort levels were observed for anxiety in the last month of life (mean SM-EOLD score 2.4) and calm in the last week of life (mean CAD-EOLD score 1.9), and the highest comfort levels for calm in the last month of life (mean SM-EOLD score 3.9) and crying in the last week of life (mean CAD-EOLD score 2.6).

**Table 1 – Characteristics of the residents with dementia in long-term care facilities in Flanders, Belgium and of their relatives (N=92)**

| CHARACTERISTICS* | N (%) |
|---|---|
| **RELATIVE** | |
| Female sex | 57 (64.8) |
| Age (mean (SD)) | 60.5 (11.0) |
| Relation to resident | |
| Spouse | 7 (7.6) |
| Child | 63 (68.5) |
| Other | 22 (23.9) |

| CHARACTERISTICS* | N (%) |
|---|---|
| **RESIDENT** | |
| Female sex | 51 (58.6) |
| Age at death (mean (SD)) | 87.5 (6.9) |
| Advanced dementia† | 45 (48.9) |
| Median length of stay in long-term care facility in years (interquartile range) | 2.1 (1.1-4.3) |

**Table 1 – continued -**

| CHARACTERISTICS* | N (%) |
|---|---|
| **RESIDENT** | |
| **Physical distress (mean (SD))** | |
| SM-EOLD physical subscale last month of life | 9.0 (4.0) |
| Pain | 1.8 (2.1) |
| Shortness of breath | 3.0 (2.2) |
| Skin breakdown | 3.9 (1.9) |
| CAD-EOLD physical distress last week of life | 8.2 (2.3) |
| Discomfort | 2.2 (0.7) |
| Pain | 2.0 (0.8) |
| Restlessness | 1.9 (0.8) |
| Shortness of breath‡ | 2.2 (0.9) |
| CAD-EOLD dying symptoms last week of life | 8.2 (2.6) |
| Shortness of breath‡ | 2.2 (0.9) |
| Choking | 2.1 (0.8) |
| Gurgling | 2.1 (0.9) |
| Difficulty swallowing | 1.8 (0.8) |
| **Psychological distress (mean (SD))** | |
| SM-EOLD psychological subscale last month of life | 18.3 (8.9) |
| Calm | 3.9 (1.9) |
| Depression | 3.2 (2.1) |
| Fear | 2.7 (2.2) |
| Anxiety | 2.4 (2.1) |
| Agitation | 2.9 (2.1) |
| Resistiveness to care | 3.4 (2.1) |
| CAD-EOLD emotional distress last week of life | 9.1 (2.3) |
| Fear | 2.2 (0.8) |
| Anxiety | 2.1 (0.8) |
| Crying | 2.6 (0.6) |
| Moaning | 2.3 (0.8) |
| CAD-EOLD well-being last week of life | 5.9 (1.9) |
| Serenity | 2.0 (0.7) |
| Peace | 2.0 (0.7) |
| Calm | 1.9 (0.7) |

SM-EOLD= Symptom Management at the End of Life with Dementia; CAD-EOLD= Comfort Assessment in Dying at the End of Life with Dementia

Item scores were reversed if the items reflected negative conditions in order to increase the interpretability: higher scores indicate better symptom control in the last month of life and more comfort in the last week of life.

* Missing values: Gender resident: N=5, Age resident: N=7, Advanced dementia: N=0, Length of stay in long-term care facility: N=4, Physical distress: N=6-15, Psychological distress: N=5-17, Gender relative: N=4, Age relative N=11, Relation to resident: N=0.

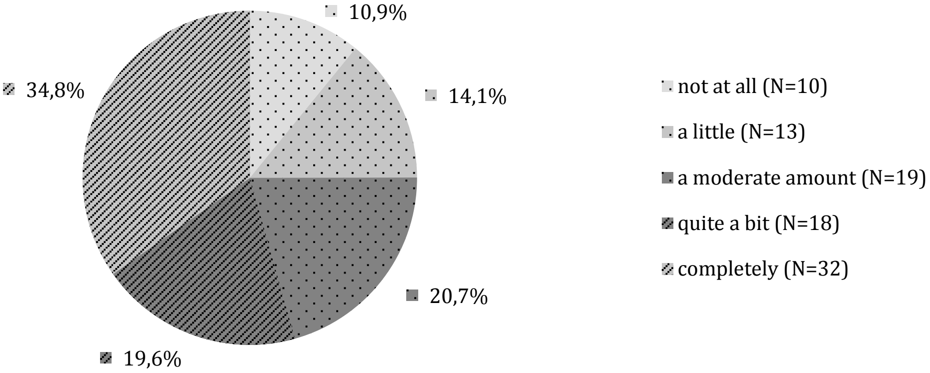
† Advanced dementia was defined as Global Deterioration Scale stage 7 and a Cognitive Performance Scale of 5 or 6.[7]

‡ The item shortness of breath is part of both the CAD-EOLD physical distress subscale and the dying symptoms subscale.

### Dying peacefully

As Figure 1 shows, 54% (N=50) of the residents died peacefully according to their relatives. Nonetheless, 11% (N=10) of relatives indicated that the resident did not die peacefully at all.

**Figure 1 – Frequency of residents with dementia dying peacefully in long-term care facilities (N=92)**



’Not at all’, ‘a little’ and ‘a moderate amount’ were seen as not dying peacefully.
‘Quite a bit’ and ‘completely’ were seen as dying peacefully.

### Correlations between dying peacefully and physical and psychological distress

Table 2 presents an overview of the correlations between dying peacefully and physical and psychological distress. With regard to the physical distress, there was a weak to moderate positive correlation between dying peacefully and the total subscale score of CAD-EOLD physical distress (r=0.37) and no to weak correlations between dying peacefully and physical symptoms in the last month of life and dying symptoms in the last week of life. As higher scores indicate better symptom control and more comfort, this means that less physical distress in the last week of life was associated with dying more peacefully. Looking at the individual items in these scales concerning physical distress, moderate positive correlations were found between dying peacefully and lower levels of discomfort in the last week of life (r=0.57), and less restlessness in the last week of life (r=0.41), and a weak positive correlation between dying peacefully and less choking in the last week of life (r=0.22). This implies that dying peacefully is associated with less discomfort, less restlessness, and less choking in the last week of life. None of the three symptoms in the SM-EOLD in the last month of life (pain, shortness of breath and skin breakdown) was significantly related to dying peacefully as perceived by the relatives.

As regards psychological distress, a moderate positive correlation was found between dying peacefully and the three total subscale scores: psychological symptoms in the last month of life (r=0.39), emotional distress in the last week of life (r=0.46), and well-being in the last week of life (r=0.44) (Table 2). Hence, dying peacefully is related to less psychological distress in the last month of life, and less emotional distress and more well-being in the last week of life. All individual items had weak to moderate positive correlations with dying peacefully, except for the following: "calm" and "resistiveness to care" in the last month of life, and "crying" in the last week of life. We found no differences regarding the significance or size of the correlation coefficient when the item "calm" was excluded from the analysis; hence, the results in Table 2 include "calm" in the SM-EOLD scale.

When comparing the correlation coefficients of subscales and items scored in the last month and last week of life, physical distress in the last week of life (r=0.37) was found to have a stronger correlation with dying peacefully than physical distress in the last month of life (r=0.06) and the dying symptoms in the last week of life (r=0.18). For psychological distress, psychological distress in the last month of life, and emotional distress and well-being in the last week of life have comparable correlation coefficients (r=0.39, r=0.46 and r=0.44 respectively, see Table 2).

**Table 2 – Correlations between dying peacefully and physical and psychological distress rated by their relatives**

| **Subscales and items** | **Dying peacefully**<br>**Spearman correlation coefficient**<br>**Relatives (N=92)[†]** |
|---|---|
| **PHYSICAL DISTRESS** | |
| **SM-EOLD physical subscale last month of life** | 0.06 |
| Pain | 0.07 |
| Shortness of breath | -0.04 |
| Skin breakdown | -0.06 |
| **CAD-EOLD physical distress last week of life** | **0.37***** |
| Discomfort | **0.57***** |
| Pain | 0.05 |
| Restlessness | **0.41***** |
| Shortness of breath[‡] | 0.14 |
| **CAD-EOLD dying symptoms last week of life** | 0.18 |
| Shortness of breath[‡] | 0.14 |
| Choking | **0.22*** |
| Gurgling | 0.04 |
| Difficulty swallowing | 0.13 |
| **PSYCHOLOGICAL DISTRESS** | |
| **SM-EOLD psychological subscale last month of life** | **0.39***** |
| Calm | 0.09 |
| Depression | **0.44***** |
| Fear | **0.35**** |
| Anxiety | **0.38**** |
| Agitation | **0.33**** |
| Resistiveness to care | 0.17 |

**Table 2 – continued -**

| **Subscales and items** | **Dying peacefully Spearman correlation coefficient Relatives (N=92)†** |
|---|---|
| **CAD-EOLD emotional distress last week of life** | **0.46***** |
| Fear | **0.45***** |
| Anxiety | **0.43***** |
| Crying | 0.20 |
| Moaning | **0.27*** |
| **CAD-EOLD well-being last week of life** | **0.44***** |
| Serenity | **0.42***** |
| Peace | **0.47***** |
| Calm | **0.28*** |

SM-EOLD= Symptom Management at the End of Life with Dementia; CAD-EOLD= Comfort Assessment in Dying at the End of Life with Dementia

Item scores were reversed if the items reflected negative conditions in order to increase the interpretability: higher scores indicate better symptom control in the last month of life and more comfort in the last week of life.

Correlations marked in bold, with 1* are significant $p<0.05$.

Correlations marked in bold, with 2 ** are significant $p<0.01$.

Correlations marked in bold, with 3 *** are significant $p <0.001$.

† Missing values between 5.4% and 18.5% (N=5-17). Missing items, with a maximum of 1 out of 3 or 4 items, were imputed with patient means to calculate a total subscale score.

‡ The item shortness of breath is part of both the CAD-EOLD physical distress subscale and the dying symptoms subscale.

## DISCUSSION

Only half of the residents (54%, 50 out of 92) died peacefully in the sample of residents in long-term care facilities in Flanders, Belgium, according to their relatives, while 11% (10 out of 92) did not die peacefully at all. Both less physical distress in the last week, and less psychological distress in the last week and last month of life were correlated with dying peacefully, however the correlations were only weak to moderate. This implies that when residents' physical and psychological distress is higher, residents are perceived to die less peacefully.

### Dying peacefully

Little research has been done regarding the percentage of residents with dementia who die peacefully in long-term care facilities. We can only compare our results to one similar study in the Netherlands, where 56% of residents with dementia died peacefully according to their relatives and 11% did not die peacefully at all,[9] percentages that are comparable to the ones found in our study.

### Dying peacefully correlated with physical and psychological distress

Our study indicates that relatives base their judgment of dying peacefully on both on physical and psychological distress. Less physical distress in the last week of life and less psychological distress in the last week and month of life were associated with dying peacefully. Correlations with psychological distress were stronger than correlations with physical distress, both in the last week of life and in the last month.

Psychological items that had significant correlations covered both the last week of life and the last month, whereas the physical symptoms with significant correlations came from the last week of life only. This shows that the last week of life is important in the perception of dying peacefully. It may be that the last week has more influence on this perception, especially when looking at the physical symptoms, which might worsen in the final days of life, whereas psychological symptoms may be more constant over time, so that a correlation can be observed for the last month as well. A lower correlation with physical distress could also be explained by the fact that the three physical symptoms in the SM-EOLD in the last month of life, namely pain, shortness of breath and skin breakdown, are quite disparate symptoms. Some authors argue that these three items should not be considered as a subscale.[18] We did calculate the correlation of the sum of these three items with dying peacefully, but there was no significant correlation.

Another interesting result is that we did not find any differences between the correlations with and those without the item “calm” from the psychological subscale of the SM-EOLD scale. We had assumed that this item would have a high correlation with dying peacefully. However, we found only a weak correlation between “calm” in the last month of life and dying peacefully, which was also rated over the last month of life.[16,17] This illustrates that physical and psychological distress often co-exist and therefore it is hard to determine how relatives interpret calmness. Some relatives might consider calmness as a solely physical aspect, whereas other relatives might include a psychological component in the item as well. This is also the case for dying peacefully itself: some relatives might see this as having reached a state of peace with oneself, looking back at the life one has had, independently of the symptoms the resident is confronted with in the actual dying process, whereas for other relatives dying peacefully might be seen as being without burdensome symptoms and being physically at rest, rather than involving psychological or existential issues.

Additionally, one could argue that the relatives who were able to say goodbye to a resident undergoing a gradual decline, for instance in the case of advanced dementia or another life-limiting and chronic disease, perceived the dying process as less stressful and therefore rated it as more peaceful, even though distressing physical or psychological symptoms might be present.

In our study, we had no information concerning the spiritual well-being of the residents with dementia and could therefore not correlate dying peacefully with spirituality, although being at peace has been correlated positively with spiritual well-being in other studies.[3-5] Nevertheless, it can be questioned to what extent spiritual well-being can be assessed in a population with dementia, and advanced dementia in particular. Research concerning spirituality in dementia mainly focused on people with dementia whose communicative skills were unimpaired or only mildly impaired;[23-25] it found that the important themes in spirituality were comparable to those of other populations of older people.

### Future research and implications for practice

We can presume that the items that were uncorrelated with dying peacefully in our study do not influence relatives' judgment of whether a death was peaceful. This study is only a first step in finding out which aspects matter most in this judgment, and we found that both psychological and physical items are correlated. To explore further how dying peacefully is perceived by relatives and what factors they consider important in their judgment, more in-depth qualitative research is needed using in-depth-interviews. This research is necessary first of all, because perception that death was not peaceful can have a negative influence on the bereavement process, for instance, and supporting family members in their bereavement process is a component of palliative care too.[26] Secondly, achieving a better understanding through future qualitative research of family members' actual perception of the characteristics of a peaceful death can provide information on how we can improve palliative care for both the dying patient and the family. So far, we do not have a complete picture of what makes a death peaceful. Nevertheless, "the percentage of relatives who indicate that the patient has died peacefully" has been proposed as a quality indicator for palliative care.[1] A quality indicator has to provide an indication of the quality of care provided. The question that remains is whether dying peacefully can be considered as a separate outcome of the quality of care provided, or whether it is more or less an indication of adequate symptom relief. To draw conclusions about whether "the percentage of relatives who indicate that the patient has died peacefully" is a useful quality indicator, more insight is needed both into the aspects of care that could influence dying peacefully and into the characteristics of a peaceful death, according to relatives.

### Strengths and limitations

As far as we know, this is one of the first studies describing the extent to which residents with dementia in long-term care facilities die peacefully. It is the first study exploring whether physical and psychological distress in the last week and month of life as perceived by relatives are correlated to their judgment of whether a death was peaceful.

Furthermore, it is a strength that this study is taking into account all residents with dementia in long-term care facilities in Flanders, regardless of the stage of dementia, as most research on dementia focuses on either the early stages or advanced dementia.

However, this study also has some limitations. We made use of ratings by proxies, which have been shown to not always be valid. On the other hand, communication with the patient might be impaired when they are in a moderate to advanced stage of dementia, leaving proxy rating as the only solution. Also, only the relatives who remain behind can judge the final outcome: the peacefulness or otherwise of the resident's death.

## CONCLUSION

This study revealed that only half by the residents in Flemish long-term care facilities died peacefully according to their relatives. This judgment of relatives of whether the resident died peacefully is related to both physical and psychological distress. Further qualitative research is needed to gain more in-depth insights into the aspects on which relatives base their judgment of dying peacefully. This way, we could gain a deeper understanding of this potentially important indicator of the quality of palliative care and discover what aspects of care can be improved.

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## REFERENCES

1. Claessen SJJ, Francke AL, Belarbi HE, Pasman HR, van der Putten MJA, Deliens L. 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.
2. Steinhauser KE, Clipp EC, McNeilly M, Christakis NA, McIntyre LM, Tulsky JA. In search of a good death: observations of patients, families, and providers. Ann Intern Med 2000;132(10):825-832.
3. Steinhauser KE, Voils CI, Clipp EC, Bosworth HB, Christakis NA, Tulsky JA. "Are you at peace?": one item to probe spiritual concerns at the end of life. Arch Intern Med 2006;166(1):101-105.
4. Steinhauser KE, Bosworth HB, Clipp EC, McNeilly M, Christakis NA, Parker J, Tulsky JA. Initial assessment of a new instrument to measure quality of life at the end of life. J Palliat Med 2002;5(6):829-841.
5. Ray A, Block SD, Friedlander RJ, Zhang B, Maciejewski PK, Prigerson HG. Peaceful awareness in patients with advanced cancer. J Palliat Med 2006;9(6):1359-1368.
6. World Health Organisation (WHO). Dementia: a public health priority. Geneva: WHO, 2012. Available at www.who.int/mental_health/publications/dementia_report_2012/en/index.html. Accessed 19th December 2014.
7. Mitchell SL, Kiely DK, Jones RN, Prigerson H, Volicer L, Teno JM. Advanced dementia research in the nursing home: the CASCADE study. Alzheimer Dis Assoc Disord 2006;20(3):166-175.
8. Houttekier D, Cohen J, Bilsen J, Addington-Hall J, Onwuteaka-Philipsen BD, Deliens L. Place of death of older persons with dementia. A study in five European countries. J Am Geriatr Soc 2010;58(4):751-756.
9. De Roo ML, van der Steen JT, Galindo Garre F, Van Den Noortgate N, Onwuteaka-Philipsen BD, Deliens L, Francke AL. When do people with dementia die peacefully? An analysis of data collected prospectively in long-term care settings. Palliat Med 2014;28(3):210-219.

10. van Uden N, Van den Block L, van der Steen JT, Onwuteaka-Philipsen BD, Vandervoort A, Vander Stichele R, Deliens L. Quality of dying of nursing home residents with dementia as judged by relatives. Int Psychogeriatr 2013;25(10):1697-1707.

11. Vandervoort A, Van den Block L, van der Steen JT, Volicer L, Vander Stichele R, Houttekier D, Deliens L. Nursing home residents dying with dementia in Flanders, Belgium: a nationwide postmortem study on clinical characteristics and quality of dying. J Am Med Dir Assoc 2013;14(7):485-492.

12. Vandervoort A, Houttekier D, Van den Block L, van der Steen JT, Vander Stichele R, Deliens L. Advance care planning and physician orders in nursing home residents with dementia: a nationwide retrospective study among professional caregivers and relatives. J Pain Symptom Manage 2014;47(2):245-256.

13. Vandervoort A, Houttekier D, Vander Stichele R, van der Steen JT, Van den Block L. Quality of dying in nursing home residents dying with dementia: does advanced care planning matter? A nationwide postmortem study. PLoS One 2014;9(3):e91130.

14. Hillmer MP, Wodchis WP, Gill SS, Anderson GM, Rochon PA. Nursing home profit status and quality of care: is there any evidence of an association? Med Care Res Rev 2005;62(2):139-166.

15. McGregor MJ, Tate RB, Ronald LA, McGrail KM. Variation in site of death among nursing home residents in British Columbia, Canada. J Palliat Med 2007;10(5):1128-1136.

16. van Soest-Poortvliet MC, van der Steen JT, Zimmerman S, Cohen LW, Klapwijk MS, Bezemer M, Achterberg WP, Knol DL, Ribbe MW, de Vet HCW. Psychometric properties of instruments to measure the quality of end-of-life care and dying for long-term care residents with dementia. Qual Life Res 2012;21(4):671-684.

17. Munn JC, Zimmerman S, Hanson LC, Williams CS, Sloane PD, Clipp EC, Tulsky JA, Steinhauser KE. Measuring the quality of dying in long-term care. J Am Geriatr Soc 2007;55(9):1371-1379.

18. Volicer L, Hurley AC, Blasi ZV. Scales for evaluation of End-of-Life Care in Dementia. Alzheimer Dis Assoc Disord 2001;15(4):194-200.

19. Reisberg B, Ferris SH, de Leon MJ, Crook T. The Global Deterioration Scale for assessment of primary degenerative dementia. Am J Psychiatry 1982;139(9):1136-1139.

20. Morris JN, Fries BE, Mehr DR, Hawes C, Phillips C, Mor V, Lipsitz LA. MDS Cognitive Performance Scale. J Gerontol 1994;49(4):M174-M182.

21. van Soest-Poortvliet M, van der Steen J, Zimmerman S, Cohen L, Reed D, Achterberg W, Ribbe M, de Vet H. Selecting the Best Instruments to Measure Quality of End-of-Life Care and Quality of Dying in Long Term Care. J Am Med Dir Assoc 2012.

22. Dancey J, Reidy J. Statistics without Maths for Psychology: using SPSS for Windows. London: Prentice Hall, 2004.

23. Mackinlay E, Trevitt C. Living in aged care: using spiritual reminiscence to enhance meaning in life for those with dementia. Int J Ment Health Nurs 2010;19(6):394-401.

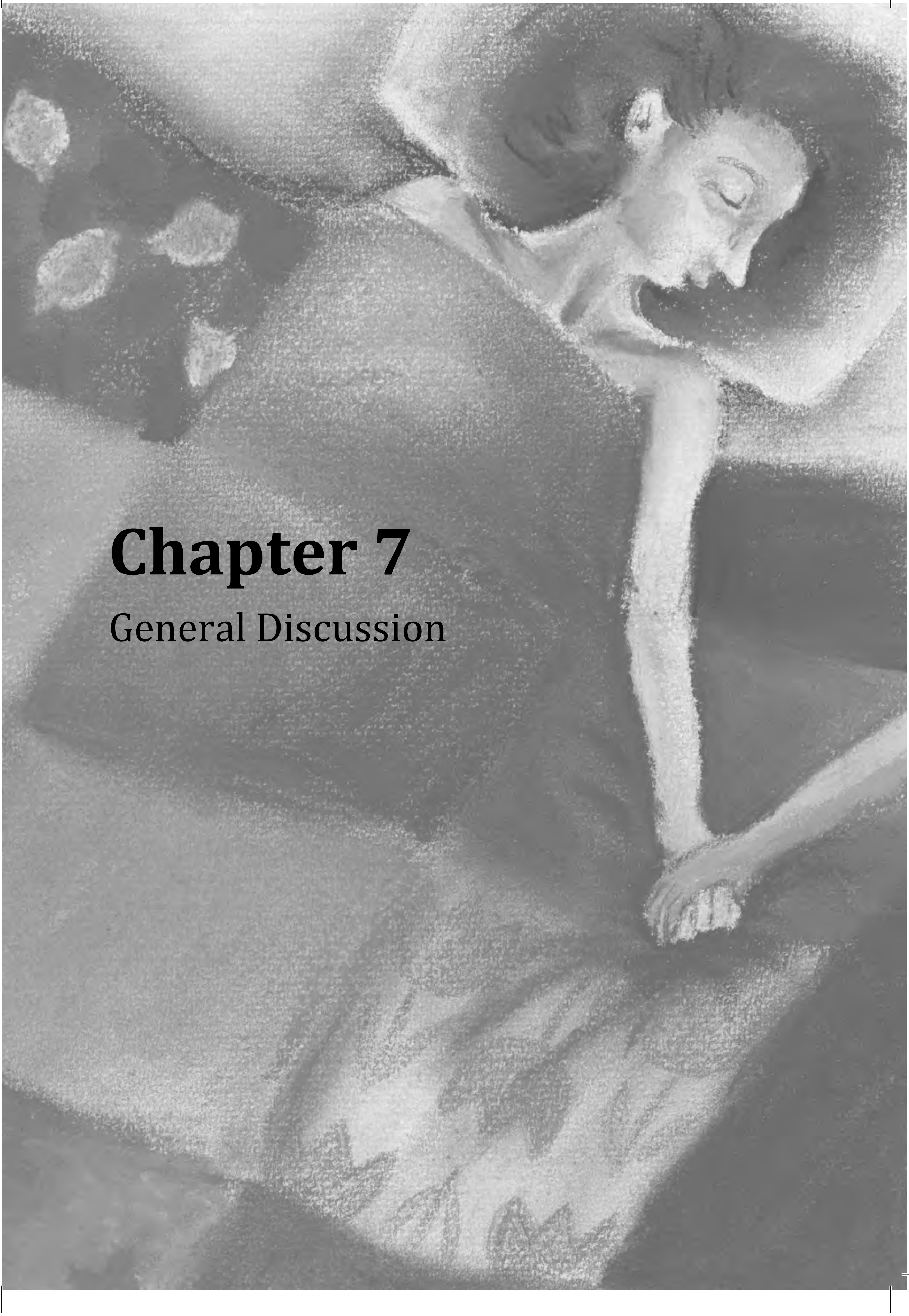
24. Beuscher L, Beck C. A literature review of spirituality in coping with early-stage Alzheimer's disease. J Clin Nurs 2008;17(5A):88-97.

25. Odbehr L, Kvigne K, Hauge S, Danbolt L. Nurses' and care workers' experiences of spiritual needs in residents with dementia in nursing homes: a qualitative study. BMC Nurs 2014;13:12.

26. World Health Organization (WHO). Definition of palliative care. 2008. Available from http://www.who.int/cancer/palliative/definition/en/. Accessed 19th December 2014.

# Chapter 7

## General Discussion



The general discussion, the final part of this thesis, will highlight and interpret the main findings. Furthermore, some methodological considerations will be formulated, as well as implications for research, clinical practice, and policy-making.

## MAIN FINDINGS

*Main findings of the systematic review on existing quality indicators for palliative care*

The international systematic review (Chapter 2) was performed to get insight into the kind of quality indicators for palliative care that have been developed so far. This review identified a substantial number of relevant indicators (17 sets of quality indicators, 326 unique quality indicators). The quality indicators mostly focus on care for specific patient populations, e.g. cancer populations or the vulnerable elderly, and on specific care settings, e.g. hospice care or palliative care in the intensive care unit.

Physical aspects of care and the structure and process of care (e.g. covering communication with patients and family) received most attention in the existing quality indicators, whereas domains concerning social, spiritual, and cultural aspects of care were covered less.

This review also explored which aspects of the framework of Donabedian, who suggested quality can be evaluated on the basis of structure, process or outcome, were covered by the existing indicators. We revealed that there were almost twice as many indicators relating to palliative care processes (mainly addressing the documentation of the care that was actually provided) as outcome indicators, and nine times as many as there were structure indicators.

Finally, we evaluated the methodological rigor of the development process and testing in practice of the quality indicator sets. The methodological quality of the indicator sets varied widely: some indicator sets have been developed in detail and widely tested in daily practice, whereas other indicator sets lack a detailed description and need further development.

*Main findings regarding the use of quality indicators in cross-country comparisons*

This part builds on two papers included in Chapters 3 and 4. We selected four quality indicators from the quality indicators found in the systematic review (Chapter 2), and applied them to existing data from a mortality follow-back study (EURO SENTI-MELC study) collected by general practitioner (GP) sentinel networks in Belgium, the Netherlands, Italy, and Spain (Castilla and León region and Valencia region).

Chapter 3 focused on two indicators concerning the place of death. These quality indicators are: “the percentage of patients dying at home” and “the percentage of patients who died in the location of their preference”. The percentage of home deaths varied between 35.3% in Belgium (N=1036), 49.1% in Italy (N=1639), 50.5% in Spain (N=565), and 50.6% in the Netherlands (N=512). None of the four countries met the performance standard of 95%, the standard that was specified in the original indicator set and developed for home palliative care services. However, not all patients in our study sample received home palliative care.

The patient’s preference for place of death was known by the GPs of only 30-60% of patients; of these patients, 67.8% died in the location of their preference in Italy (N=485), 72.6% in Belgium (N=437), 75.4% in the Netherlands (N=303), and 86.0% in Spain (N=165). So far, no performance standard has been specified for this indicator, but it has been suggested to use a best-practice norm.

In Chapter 4, the following quality indicators concerning hospitalizations in the last month of life were studied: “the percentage of time spent in hospital” and “the proportion (of patients) with more than one hospitalization in the last 30 days of life”. The scores calculated here for the first quality indicator were that 14.1% of time was spent in hospital during the last month of life in the Netherlands (N=310), 17.7% in Spain (N=224), 22.2% in Italy (N=764), and 24.6% in Belgium (N=500). This implies that the performance standard of less than 10% of time spent in hospital was not met in the four countries. The proportion of patients with more than one hospitalization was 0.6% in the Netherlands (N=310), 3.1% in Italy (N=764), 4.0% in Spain (N=224) and 5.4% in Belgium (N=500). Consequently, the Netherlands and Italy met the existing performance standard of fewer than 4% of patients hospitalized more than once in the last month of life.

We also investigated the feasibility of measuring these quality indicators based on data gathered by the GP sentinel networks. The quality indicator scores regarding home deaths, frequency of hospitalizations in the last month of life, and duration of hospitalizations in the last month of life could be calculated from the data from the GP sentinel networks, since the number of missing values was low. On the other hand, the quality indicator describing whether patients died at their location of preference had a high proportion of missing values, since GPs only knew where their patient wanted to die in 30-60% of cases, showing that exploring patient’s preferences may be a challenging process.

Quality indicators should reflect the quality of care provided rather than patient characteristics. We therefore also investigated whether expected differences in quality indicator scores are related to actual differences in the care provided or the organization of care in Belgium, the Netherlands, Italy, and Spain. Receiving palliative care from the GP was positively associated with both dying at home in a population of home-dwelling patients who died non-suddenly in all four countries, and with dying at the location of preference in Belgium, the Netherlands, and Italy. Some care goals in the last 2-4 weeks of life were significantly associated with dying at home. If cure was an important care goal in the last weeks of life, people were less likely to die at home (significant association in Belgium and Spain). In addition, if prolonging life was an important goal in the last weeks of life, people were less likely to die at home (significant association in Italy and Spain).

For the quality indicator scores concerning the frequency and duration of hospitalizations in the last month of life, we studied only data of cancer patients. We compared the data of home-dwelling cancer patients who died non-suddenly and received palliative care from GPs with the data of a group of cancer patients who did not receive palliative care from their GP. The time spent in hospital in the cancer patient group who did receive palliative care from their GP was significantly lower than for the group who did not, in all four countries. There were fewer rehospitalizations among the group of cancer patients who received GP palliative care, although this difference was only significant in Italy.

The differences between countries in these four indicators seem to reflect country-specific differences in the organization of palliative care.

### *Main findings on quality indicators for palliative care for residents with dementia in long-term care facilities*

The quality indicator “the percentage of relatives who indicate that the patient died peacefully” was identified in the systematic review in Chapter 2 and subsequently calculated for the data of two studies concerning the quality of dying in residents with dementia in long-term care facilities in two countries: the Dutch End of Life in Dementia study (the Netherlands) and the Dying Well with Dementia in Flanders study (Belgium). Besides calculating the quality indicator score, we investigated which characteristics of the resident, of the palliative care provided, and of the specific care facility were associated with dying peacefully.

In the Netherlands, only half of the residents with dementia in long-term care facilities died peacefully (56.2%, see Chapter 5) according to their relatives, whereas 11% of relatives indicated that the resident did not die peacefully at all. The percentage of residents who died peacefully differed between the different long-term care facilities, ranging from 17% to 80%, with most facilities having a percentage between 30% and 64%. Comparable figures are found in Flanders, where 54.4% of residents with dementia in long-term care facilities died peacefully (see Chapter 6), and 11% did not die peacefully at all.

A second goal of Chapters 5 and 6 was to assess the characteristics of the resident, of the palliative care provided, and of the specific care facility that are associated with dying peacefully. Concerning the characteristics of the residents, it was revealed that relatives' judgment that the resident with dementia had an optimistic attitude was associated positively with dying more peacefully (Chapter 5). Relatives' judgments that patient had less physical distress in the last week, or less psychological distress in the last week and last month of life, were weakly to moderately correlated with dying more peacefully (Chapter 6).

When correcting for the resident's characteristics, dying peacefully was not related to any of the care characteristics, while it was associated with two of the facility characteristics we measured in Chapter 5. Residents were more likely to die peacefully if family members felt that enough nurses were available. In addition, if elderly care physicians perceived that there was a moderate influence of religious affiliation, on the facilities' end-of-life decision-making policies, rather than no influence, residents were more likely to die peacefully.

## REFLECTIONS ON THE MAIN FINDINGS

### *Quality indicators cover all domains of palliative care, but coverage is unequal*

The indicators found in the systematic review (Chapter 2) mostly addressed "physical aspects" of care and the "structure and process" of care, while domains like "spiritual, religious, and existential aspects" of care and "cultural aspects" of care were underrepresented. This unequal distribution of the indicators across domains of palliative care could be a reflection of the fact that daily practice pays more attention to aspects such as symptom management and communication, and less to social, spiritual, and cultural aspects. On the other hand, this underrepresentation might also be due to the fact that developing indicators for some of the domains might be a challenge, for instance because some of these issues are not routinely reported or are inconsistently reported in the usual data sources,[1,2] or because the emphasis is on indicators that have to be quantifiable.[3] However, it is important to measure what we want to know, and not only what is easy to count,[4] and therefore, if we respect the WHO definition that declares that social, spiritual, and cultural aspects are an essential part of palliative care,[5] the necessary attention should be paid to these aspects in quality indicators as well. Consequently, the five quality indicators used in this thesis concern both palliative care domains for which many quality indicators have been developed ("structure and process of palliative care") and domains that have received less attention in quality indicators so far ("care for the imminently dying patient" and "spiritual, religious, and existential aspects of care").

### *Structure, process, and outcome indicators all have advantages and disadvantages*

The structure, processes, and outcomes of care were addressed in the indicators found by the systematic review, although processes and outcomes received more attention than the structure of care. All types of indicators have advantages and disadvantages, leading to the suggestion by many authors that a quality indicator set that is broad and comprehensive should include structure, process *and* outcome indicators.[6-10] Some authors suggested that it might be easier and cheaper to derive quality indicators concerning processes and structure of care from existing data such as medical records and administrative data or data that is routinely collected.[10] However, this thesis has shown that the five outcome indicators we studied could also be derived from existing data that was not collected primarily with a view to measuring quality. Outcome indicators based on the patient's and family's perspective can be an extra burden on patients and family members because of the need to collect data from them,[11-13] but have the advantage of providing information from their perspective, which is an important component in the assessment of the quality of palliative care.

One Dutch quality indicator set,[14] of which we used two indicators in this thesis, focuses primarily on outcomes because the developers felt this should be the main focus of assessment, whereas it is the responsibility of care providers themselves to organize the structures and processes of care in such a way that the desirable outcomes are achieved.[14] However, particularly when poor outcomes are measured, it is an advantage if information about processes and structures that are linked to this outcome is available as well, so that this information can be used to improve practice. Therefore, if processes and structures are measured along with outcome indicators, targeted improvement measures can be taken in order to achieve better outcomes.

### *Differences in quality indicator scores between countries are related to differences in care and policy*

Ideally, quality indicators reflect the quality of care rather than being related to clinical and other characteristics of the patients, or measurement differences.[11,14-18] Statistical case-mix adjustment procedures take the confounding patient characteristics into account, so that quality indicator scores do reflect actual differences in the quality of care.[15,17] If quality indicators scores are indeed related to care characteristics, influencing these aspects of care may lead to quality improvement. Comparing the quality indicator scores between countries can help identify opportunities not only to improve practice in various countries,[19] but also to change healthcare policies in these countries.

In Chapters 3 and 4, we checked whether the countries being studied differed in terms of gender, age at death, cause of death or cancer type and diagnosis of dementia. Quality indicator scores were standardized if necessary. We showed that quality indicator scores varied considerably among the countries. The differences between the countries found for these four indicators seem to reflect country-specific differences in the organization of palliative care, confirming their role as quality indicators for palliative care.

### *Differences in quality indicators scores are linked to differences in facility characteristics*

In Chapter 5, we revealed that dying peacefully among residents with dementia in Dutch long-term care facilities was linked to two facility characteristics of the nursing homes, when adjusting for resident characteristics. Firstly, residents were more likely to die peacefully if family members felt that enough nurses were available. The quality and quantity of personnel are indeed important for the quality of care, although they are not the only determinants. Personal attention and a respectful attitude towards patients are important aspects of care[20,21] that were measured in this study as well; they were associated with dying peacefully in the univariable model (correcting for resident characteristics). Surprisingly, these care characteristics were not significantly associated with dying peacefully in the multivariable model, which suggests that these care characteristics are dependent on other care and facility characteristics. Secondly, if elderly care physicians perceived that there was a moderate influence of a facility’s religious affiliation on the end-of-life decision-making policies, residents were more likely to die peacefully compared to facilities without a religious affiliation or facilities where no influence was observed. This was not observed when there was a strong perceived influence of a facility’s religious affiliation. The exact mechanism of this moderate influence of a facility's religious affiliation on the end-of-life decision-making policies, however, is unclear.

So far, it is also unclear what aspects relatives base their judgment of a peaceful death on. In Chapter 6, we revealed that their perception is related to both physical and psychological distress, but this does not give the whole picture. Some relatives might see dying peacefully as having reached a state of peace with oneself, looking back on the successful and rewarding life one has had, regardless of the symptoms the resident was confronted with in the last phase of life, whereas other relatives might take burdensome symptoms and being physically at rest into account in their judgment, rather than taking psychological or existential issues into account. This raises the question whether dying peacefully is a separate outcome of palliative care, or whether it functions as an indicator of adequate symptom management, leaving the question open of whether "the percentage of relatives who indicate that the patient has died peacefully" can be used as a quality indicator for palliative care.

## REFLECTIONS ON THE RESEARCH METHODS

### *Methodological reflections about the systematic review (Chapter 2)*

Systematic reviews synthesize existing research findings at that moment,[22] providing caregivers in the field, researchers, and policy makers with an overview of existing evidence. Therefore, systematic reviews should be updated regularly,[22,23] especially in fields where new relevant research has become available. This is the case for quality indicators in palliative care, a subject that has received growing attention in recent years, both in literature and in policy.[24-29] Accordingly it was decided to update an existing systematic review on quality indicators for palliative care[26] in this thesis.

Since the publishing process of systematic reviews in peer-reviewed journals takes time, it might be that new evidence has been published in the meantime, making the systematic review no longer completely up to date. Another frequently mentioned limitation of most systematic reviews is that they are performed using international databases that mainly contain scientific peer-reviewed literature and the reviews therefore could miss some of the 'gray' literature. We cannot exclude this possibility, but since we found some gray literature when manually checking the references of the articles included, we expect to have kept the number of relevant articles that have been missed to a minimum.

*Methodological reflections about the studies presented in Part 2 and 3 (Chapters 3-6)*

It is a major advantage that we were able to calculate quality indicator scores for five quality indicators based on data gathered by existing general practitioner sentinel networks (Chapters 3 and 4) and data concerning residents with dementia in long-term care facilities from two different studies (Chapters 5 and 6), although the primary aim of the original data collection was not to calculate quality indicator scores. We were also able to reveal associations between quality indicator scores and the care and facility characteristics that were measured in these data. This shows that using existing data to calculate quality indicator scores, as we did in this thesis, enables substantial information to be obtained on the quality of care provided without major data collection efforts and at low costs.[9,30,31] Therefore, it is useful to look at existing data when wishing to calculate a quality indicator score. If existing data is available and provides the necessary information to calculate the score of a selected quality indicator, it would be a waste of time and resources to collect new data for this purpose.

However, some pitfalls need to be taken into account when using existing data. A first pitfall is the fact that information retrieved from existing databases can be limited, especially in terms of the patient's symptom burden, the patient's preferences, communication issues or care processes that have taken place. We only selected databases that we thought would contain at least some useful information to calculate quality indicator scores and to give insights into relationships with the actual care provided.

A second pitfall is that using existing data, for instance collected routinely for administrative purposes, could exclude patients' and family members' subjective perspectives, both important perspectives when it comes to quality.[5,32] Indeed, in this thesis we do not have information from the patient's perspective, but we were able to use data concerning residents with dementia in long-term care facilities taken from structured post-mortem questionnaires completed by family members, without the disadvantage of imposing a substantial burden on patients at the end of life.[9,31]

A third pitfall is that the quality of the information in the original study and data determines the quality of the calculated quality indicator scores.[17,30,32,33] In Chapters 3 and 4, data were gathered by GP sentinel networks. Recall bias was limited due to weekly registrations and because GPs were instructed to complete the questionnaire immediately after being informed of the death. We cannot verify the accuracy of GPs' evaluation of deaths as not being sudden and unexpected, nor can we verify whether GPs provided palliative care or not, or whether they were informed of all care transitions at the end of life. Inaccuracies and socially desirable answers cannot therefore be completely ruled out.

It is worth mentioning here that it was hard to interpret the quality indicator concerning preferred place of death given the substantial proportion of preferences unknown to the GPs, probably because the preferred place of death is often not discussed with patients. Although communication about end-of-life preferences is considered important, and GPs know the importance of proactive communication, they may find it hard to find the right time to talk about this kind of preferences.[34-37] This quality indicator score concerning dying at the preferred place of death is very likely an overestimation. It has been shown in other studies that when GPs know the preferred place of death, this is associated with patients dying at their place of preference and that the same determinants apply for both the GP knowing the preference and the patient dying at the preferred place of death.[38,39]

In Chapters 5 and 6 of this thesis, we used professional caregivers and relatives as proxies for the patient. These chapters consider the indicator concerning dying peacefully as perceived by relatives of residents with dementia. Use of relatives as proxies is a logical choice, not only because the residents' cognition and communication might be impaired, but also because when it comes to a peaceful death, relatives might be in the right position to judge and report their judgment, as they are the ones who remain behind after the resident's death.

## REFLECTIONS ON THE METHODOLOGICAL PROPERTIES OF QUALITY INDICATORS

### *Quality indicators measure care at an aggregate level, not at the patient level*

Defining what constitutes good quality of palliative care is not that easy.[40,41] Looking at quality indicators concerning place of death and preferred place of death, for instance, there has been a debate about whether a home death can be seen as the golden standard since that is where most people want to die,[42-45] or whether looking at the preferred place of death is a better option.[42,46-49] Or looking at time spent in hospital versus the frequency of rehospitalizations in the last month of life as indicators of the quality of care delivered.[3,40,50] Healthcare professionals must understand that if a performance standard is not met, this does not mean that care for an individual patient or care by the responsible caregiver "failed". For an individual patient, deviating from the care proposed in the quality indicator could mean better individual care. However, quality indicators are meant to judge care not at this individual level, but at the meta-level, often at the level of a care organization or facility.[6,50-52]

*The performance standards defined for quality indicators are often not realistic*

The four countries we studied (Chapter 3 and 4) often did not meet the performance standards defined by the original developers of the indicator sets described in our systematic review. In general, fully meeting a performance standard may not be feasible, since palliative care is a complex form of care that should be tailored to the patient's needs and therefore there will always be exceptions in individual cases even when the best care is provided. Defining a performance standard is a complex issue.[30] Performance standards can be perceived in several ways: 1) as a basic level of quality, which ideally all settings or countries should achieve; 2) as a higher quality level, a level that should be reached if the improvement strategies work; 3) as an innovative level, that might not seem achievable at present, but that could become the optimal level in the future.[53] Striving to meet this innovative quality level should be the aim in the long term, but more feasible performance standards are needed in the meantime. In this regard, it may be a good thing to use best-practice norms as performance standards rather than absolute norms. Absolute norms are often defined by experts, while best-practice norms are derived from the scores of the lower limit of the upper quartile of care providers, for instance. The fact that best-practice norms are derived from scores in actual practice makes them realistic and motivates healthcare professionals to assess and improve quality.

*Whether national performance standards are needed, depends on the subject of the quality indicator*

Quality indicators were originally developed for comparisons or monitoring at the level of care organizations rather than for cross-country comparisons. Whether one performance standard fits different countries is open to question. For some types of quality indicators, for instance those addressing pain relief, one could argue that people should receive optimal pain relief regardless of the country where they are cared for, and thus one performance standard could be defined for all countries. However, for quality indicators directly related to national healthcare policies, e.g. quality indicators on hospitalizations or place of death, one could argue that defining a performance standard at a national level could be more appropriate.

## IMPLICATIONS FOR RESEARCH

*Existing quality indicators should be developed further instead of developing new indicators*

Using and adapting existing quality indicators that have already been tested for validity and feasibility would be ideal[2,27] and would limit unnecessary efforts to develop new indicators. Our suggestion is therefore not to create completely new indicators, but to use, adjust, and validate existing indicators in other settings and countries. The transfer of quality indicators from one country to another has been shown to be feasible,[54,55] as long as these quality indicators are critically evaluated and adapted to the national or local context where needed.

An exception here is the domains concerning social, spiritual, and cultural aspects of care that are underrepresented among the existing indicators. For these domains, new quality indicators could be developed if the existing quality indicators do not cover the domains sufficiently.

*Development process of quality indicators should be described in detail*

The development process and testing in practice of quality indicators for palliative care should be described in more detail in order to avoid the constant development of new, overlapping sets of indicators and to promote the transfer of quality indicators between settings and countries.

Firstly, the scientific evidence on which the indicators are based should be described.[7,56] In the case of the further development of existing indicators, an inventory of existing indicators concerning the aspects that one wants to study is a good starting point.[10,14]

Secondly, quality indicators also need to be clinically relevant and usable,[7,10,14,56] therefore involvement of all the relevant stakeholders, including policy-makers, professional and informal caregivers, and patients and families, is important and should be disclosed.[10,14] These expert panels can not only judge whether the potential indicators are relevant, but can also help prioritize and select quality indicators to obtain a comprehensive quality indicator set.

Thirdly, it is also important to specify how the actual quality indicator should be measured, for instance by specifying a measurement instrument to assess symptoms, and how the quality indicator score should be calculated, by defining a numerator and denominator.

*Existing quality indicators should be further tested and used in practice*

The developed sets should then be tested in practice in a pilot, or in the case of the further development of existing indicators, be tested in a different care setting or country for instance, for feasibility and usability.[10,14] If found to be feasible and usable in this test, these quality indicators should be tested and used in larger samples. Using existing quality indicators in practice offers many advantages. Firstly, this will provide more insights into the methodological properties of these indicators, improving the methodological rigor of these quality indicators. Special attention should be paid to feasibility, validity (do these quality indicator scores reflect actual differences in the quality of care?), and discriminative power (are the quality indicators able to reveal existing differences between different care settings?).[10,14]

Secondly, further use in practice will also allow researchers to develop good case-mix adjustment procedures that will let them control for differences in patient and measurement characteristics and thus provide quality indicator scores that are linked to actual differences in the care provided.

Thirdly, testing in larger samples will provide more insights into best-practice norms, leading to the definition of realistic performance standards that can be used in quality improvement initiatives to stimulate quality improvement.

When testing and using quality indicators, care professionals and care providers should cooperate with researchers, asking for feedback about the performance of the quality provided in their care settings and countries. If research reveals associations with certain care processes, or forms of care organization and funding, healthcare professionals and policy-makers should use this information in order to make optimum use of quality indicator data for quality improvement.

*A deeper understanding of dying peacefully and its function as a quality indicator is needed*

One example of this thesis where further research is needed is the quality indicator “the percentage of relatives who indicate that the patient has died peacefully”. Dying peacefully is generally considered as an outcome of high-quality palliative care, but only little is known about what constitutes a peaceful death and how relatives perceive whether a patient dies peacefully. In future research, a qualitative approach seems most suitable, so that in-depth information can be obtained to identify factors that play a role in the relatives’ perception of dying peacefully. This deeper understanding could benefit both the care for patients at the end of life and the support or bereavement care for relatives. However, dying peacefully should be used as a quality indicator in the future only if it can be influenced by the care provided. If this is the case, the potential of “the percentage of relatives who indicate that the patient has died peacefully” as a quality indicator that emerged from our study in Dutch long-term care facilities should be evaluated further in other countries. In particular, proper attention should be paid to testing associations with care and facility characteristics, correcting for differences in patient case mix, and investigating the discriminative power of this indicator (i.e. whether this indicator can reveal differences between facilities).

## IMPLICATIONS FOR POLICY AND PRACTICE

*International organizations should encourage the identification and use of a minimum comprehensive set of quality indicators*

First of all, international organizations such as the World Health Organization, the Council of Europe, and the European Association for Palliative Care should promote the use of quality indicators. With regard to this, a minimum set of quality indicators that are suitable for comparisons between countries and settings should be identified.[4] Providing such a fully representative set might be an impossible challenge to meet,[2,57] but ideally this set should aim to give a representative picture of the quality of palliative care as a whole. Therefore, quality indicators included in this set need to cover different domains and levels of palliative care, as well as structures, processes, and outcomes of care. Development of such an indicator set needs to strike a balance between using indicators in the most rigorous way and what is feasible and practical in reality: the set must not be too time-consuming, should be feasible in terms of financial and staffing resources, and must not be too burdensome for patients, family, and healthcare professionals.[2,52,57] On the other hand, too much emphasis on minimizing recording and collection efforts and limiting the number of indicators should be avoided, as this narrows the aspects of care that can be evaluated.[58]

Secondly, these international organizations should encourage data collection for this minimum quality indicator set on a national level and facilitate the sharing and distribution of these data.[24,31] These national quality indicator scores should be made transparent, for instance in annual reports by these organizations, or in reports on the development of palliative care, for instance the Palliative Care Atlas by the European

Association for Palliative Care. This way, collaboration between national initiatives for quality improvement could lead to lessons being learned from cultural differences and differences in care organization between countries,[27] promoting an accelerated diffusion of effective programs.[31]

In addition, cross-country comparisons of the quality indicator scores for the minimum indicator set should also be used by international organizations to establish realistic performance standards for countries based on best-practice norms. Policy-makers from a country with suboptimal performance could be inspired by policies of other countries that score better on certain quality indicators and could consequently change or adapt their own policies. In this regard, it is worth mentioning that the appropriateness of one performance standard for different countries could be questioned for some aspects of care. Depending on the aspect of care studied, national governments should define or adapt performance standards according to the priority they give this aspect in their national policies and according to their best practices.

*National governments should invest in infrastructure and resources for data collection*

On a national level, data should be collected to measure the quality of care provided. Preferably, national policy-makers should invest in existing registration systems and data collection structures, linking the collection of information for extra quality indicators to these systems and creating a measurement system that can be sustained without too much additional cost and effort. Several authors have expressed the need to standardize death-certificate data in this regard, to enhance comparable data collection and comparisons between countries.[31,59,60] Basic administrative and insurance data that are routinely collected could also be informative for quality indicator calculations.[31] As we have shown, existing sentinel networks[61] can also provide complementary information regarding the circumstances of death and care provided to patients, without much extra effort.

*Measuring the quality of palliative care with accurate quality indicators is only the first step in quality improvement*

Measuring quality indicators to get insights into the quality of care provided, is only the first step in improving quality. Practicing healthcare professionals should not only be actively involved in the measurement of indicators, they should also appraise their care setting or country critically and learn from suboptimal quality indicator scores. Quality indicator scores that did not meet the performance standards should be used as an opportunity to evaluate the organization and provision of palliative care, helping to identify areas that need improvement. Ideally, quality improvement strategies to overcome this suboptimal quality should follow.

After being properly tested in practice, the next step could then be to implement quality indicators in practice, in order to use these indicators to monitor the quality of palliative care.[62,63] This does not mean that all indicators have to be measured continuously or daily, but care organizations have to consider how they can evaluate the quality of the care provided on a regular basis, for instance every one or two years. For an effective implementation, a precise implementation plan is needed, and facilitators and barriers to implementing quality indicators should be identified beforehand.[62,63] After implementation, the quality indicators used need to be evaluated regularly as well, to see if they are still relevant and performance standards are still up to date.

## CLOSING REMARKS

This thesis focused on quality indicators that can be used to assess and subsequently improve the quality of palliative care, from an international point of view. We were able to derive quality indicators from existing datasets collected for other purposes and to use these indicators in cross-country comparisons. We used these findings to formulate recommendations for future research, clinical practice, and international and national policy-makers. We hope that this thesis can be a source of inspiration, leading to new opportunities to achieve lasting, wide-spread research on quality and improvements in palliative care.

## REFERENCES

1. Bausewein C, Daveson B, Benalia H, Simon S, Higginson I. Outcome Measurement in Palliative Care: The Essentials. http://www.eapcnet.eu/LinkClick.aspx?fileticket=-T62WTgTHtU%3d&tabid=1577. Accessed 19th December 2014; 2011.
2. Dy SM. Measuring the quality of palliative care and supportive oncology: principles and practice. J Support Oncol 2013;11(4):160-164.
3. Peruselli C, Marinari M, Brivio B, Castagnini G, Cavana M, Centrone G, Magni C, Merlini M, Scaccabarozzi GL, Paci E. Evaluating a home palliative care service: development of indicators for a continuous quality improvement program. J Palliat Care 1997;13(3):34-42.
4. Payne S, Leget C, Peruselli C, Radbruch L. Quality indicators for palliative care: debates and dilemmas. Palliat Med 2012;26(5):679-680.
5. World Health Organisation (WHO). Definition of Palliative Care. http://www.who.int/cancer/palliative/definition/en/. Accessed 19th December 2014; 2002.
6. Donabedian A. The quality of care. How can it be assessed? JAMA 1988;260(12):1743-1748.
7. Campbell SM, Braspenning J, Hutchinson A, Marshall MN. Research methods used in developing and applying quality indicators in primary care. BMJ 2003;326(7393):816-819.
8. Mainz J. Defining and classifying clinical indicators for quality improvement. Int J Qual Health Care 2003;15(6):523-530.
9. Seow H, Snyder CF, Mularski RA, Shugarman LR, Kutner JS, Lorenz KA, Wu AW, Dy SM. A framework for assessing quality indicators for cancer care at the end of life. J Pain Symptom Manage 2009;38(6):903-912.
10. Leemans K, Cohen J, Francke AL, Vander Stichele R, Claessen SJ, Van den Block L, Deliens L. 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;12:6.
11. Brook RH, McGlynn EA, Shekelle PG. Defining and measuring quality of care: a perspective from US researchers. Int J Qual Health Care 2000;12(4):281-295.
12. Morrison RS, Siu AL, Leipzig RM, Cassel CK, Meier DE. The hard task of improving the quality of care at the end of life. Arch Intern Med 2000;160(6):743-747.
13. Rubin HR, Pronovost P, Diette GB. The advantages and disadvantages of process-based measures of health care quality. Int J Qual Health Care 2001;13(6):469-474.
14. Claessen SJJ, Francke AL, Belarbi HE, Pasman HR, van der Putten MJA, Deliens L. 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.
15. Beersen N, Kallewaard M, van Croonenborg J, van Everdingen J, van Barneveld T. Handleiding indicatorontwikkeling [Manual for Development of Indicators]. Kwaliteitsinstituut voor de Gezondheidszorg (CBO) [Quality Institute for Health Care]. http://www.zonmw.nl/nl/programmas/programma-detail/kiezen-in-zorg/consumenteninformatie-en-transparantie/. Accessed 19th December 2014; 2007.
16. Bausewein C, Daveson B, Currow D, Downing J, Deliens L, Radbruch L, et al. EAPC White paper on Outcome Measurement in Palliative Care: Improving Practice, Attaining Outcomes and Delivering Quality Services (in press). http://www.eapcnet.eu/Themes/Clinicalcare/Outcomemeasurement/Publicationsdocuments.aspx; 2014.
17. Powell AE, Davies HTO, Thomson RG. Using routine comparative data to assess the quality of health care: understanding and avoiding common pitfalls. Qual Saf Health Care 2003;12(2):122-128.
18. Currow DC, Eagar K, Aoun S, Fildes D, Yates P, Kristjanson LJ. Is it feasible and desirable to collect voluntarily quality and outcome data nationally in palliative oncology care? J Clin Oncol 2008;26(23):3853-3859.

19. Gigli A, Warren JL, Yabroff KR, Francisci S, Stedman M, Guzzinati S, Giusti F, Miccinesi G, Crocetti E, Angiolini C, Mariotto A. Initial treatment for newly diagnosed elderly colorectal cancer patients: patterns of care in Italy and the United States. J Natl Cancer Inst Monogr 2013;2013(46):88-98.

20. Francke AL, Willems DL. Terminal patients' awareness of impending death: the impact upon requesting adequate care. Cancer Nurs 2005;28(3):241-247.

21. Claessen SJJ, Francke AL, Sixma HJ, de Veer AJE, Deliens L. Measuring patients' experiences with palliative care: the Consumer Quality Index Palliative Care. BMJ Support Palliat Care 2012;2(4):367-372.

22. Moher D, Tsertsvadze A, Tricco AC, Eccles M, Grimshaw J, Sampson M, Barrowman N. When and how to update systematic reviews. Cochrane Database Syst Rev 2008;(1):MR000023.

23. Moher D, Tsertsvadze A, Tricco AC, Eccles M, Grimshaw J, Sampson M, Barrowman N. A systematic review identified few methods and strategies describing when and how to update systematic reviews. J Clin Epidemiol 2007;60(11):1095-1104.

24. Council of Europe. Recommendation Rec (2003) 24 of the Committee of Ministers to member states on the organisation of palliative care. CM 2003;130.

25. EAPC Taskforce on patient-reported outcome measurement in palliative care. http://www.eapcnet.eu/Themes/Clinicalcare/Outcomemeasurement.aspx. Accessed 19th December 2014; 2012.

26. Pasman HR, Brandt HE, Deliens L, Francke AL. Quality indicators for palliative care: a systematic review. J Pain Symptom Manage 2009;38(1):145-156.

27. Ostgathe C, Voltz R. Quality indicators in end-of-life care. Curr Opin Support Palliat Care 2010;4(3):170-173.

28. National Consensus Project for Quality Palliative Care (2013). Clinical Practice Guidelines for Quality Palliative Care, Third Edition. http://www.nationalconsensusproject.org. Accessed 19th December 2014; 2013.

29. World Health Organisation (WHO) and World Palliative Care Alliance (WPCA), Connor S, Sepulveda Bermedo M, (editors). Global Atlas of Palliative Care at the End of Life. http://www.who.int/nmh/Global_Atlas_of_Palliative_Care.pdf. Accessed 19th December 2014; 2014.

30. Grol R, Wensing M. Kwaliteit en veiligheid in de zorg: de rol van indicatoren [Quality and safety of Care: the role of indicators]. Implementatie: Effectieve verbetering van de patiëntenzorg [Implementation: Effective improvement of patient care]. 4 ed. Amsterdam: Reed Business; 2011. p. 195-228.

31. 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(11):1765-1771.

32. Fowler FJJ, Coppola KM, Teno JM. Methodological challenges for measuring quality of care at the end of life. J Pain Symptom Manage 1999;17(2):114-119.

33. Benin AL, Fenick A, Herrin J, Vitkauskas G, Chen J, Brandt C. How good are the data? Feasible approach to validation of metrics of quality derived from an outpatient electronic health record. Am J Med Qual 2011;26(6):441-451.

34. Evans N, Pasman HR, Vega Alonso T, Van den Block L, Miccinesi G, Van Casteren V, Donker G, Bertolissi S, Zurriaga O, Deliens L, Onwuteaka-Philipsen B. End-of-life decisions: a cross-national study of treatment preference discussions and surrogate decision-maker appointments. PLoS One 2013;8(3):e57965.

35. Evans N, Costantini M, Pasman HR, Van den Block L, Donker GA, Miccinesi G, Bertolissi S, Gil M, Boffin N, Zurriaga O, Deliens L, Onwuteaka-Philipsen B. End-of-life communication: a retrospective survey of representative general practitioner networks in four countries. J Pain Symptom Manage 2014;47(3):604-619.

36. Claessen SJJ, Francke AL, Echteld MA, Schweitzer BPM, Donker GA, Deliens L. GPs' recognition of death in the foreseeable future and diagnosis of a fatal condition: a national survey. BMC Fam Pract 2013;14:104.

37. De Korte-Verhoef M, Pasman H, Schweitzer B, Francke A, Onwuteaka-Philipsen B, Deliens L. General practitioners' perspectives on the avoidability of hospitalizations at the end of life: A mixed-method study. Palliat Med 2014;28(7):949-958.

38. Meeussen K, Van den Block L, Bossuyt N, Bilsen J, Echteld M, Van Casteren V, Deliens L. GPs' awareness of patients' preference for place of death. Br J Gen Pract 2009;59(566):665-670.

39. Abarshi E, Onwuteaka-Philipsen B, Donker G, Echteld M, Van den Block L, Deliens L. General practitioner awareness of preferred place of death and correlates of dying in a preferred place: a nationwide mortality follow-back study in the Netherlands. J Pain Symptom Manage 2009;38(4):568-577.

40. Earle CC, Neville BA, Landrum MB, Souza JM, Weeks JC, Block SD, Grunfeld E, Ayanian JZ. Evaluating claims-based indicators of the intensity of end-of-life cancer care. Int J Qual Health Care 2005;17(6):505-509.

41. Rosenfeld K, Wenger NS. Measuring quality in end-of-life care. Clin Geriatr Med 2000;16(2):387-400.

42. Billingham MJ, Billingham SJ. Congruence between preferred and actual place of death according to the presence of malignant or non-malignant disease: a systematic review and meta-analysis. BMJ Supportive & Palliative Care 2013;3(2):144-154.

43. Bell CL, Somogyi-Zalud E, Masaki KH. Methodological review: measured and reported congruence between preferred and actual place of death. Palliat Med 2009;23(6):482-490.

44. Gomes B, Higginson IJ, Calanzani N, Cohen J, Deliens L, Daveson BA, Bechinger-English D, Bausewein C, Ferreira PL, Toscani F, Menaca A, Gysels M, Ceulemans L, Simon ST, Pasman HRW, Albers G, Hall S, Murtagh FEM, Haugen DF, Downing J, Koffman J, Pettenati F, Finetti S, Antunes B, Harding R. Preferences for place of death if faced with advanced cancer: a population survey in England, Flanders, Germany, Italy, the Netherlands, Portugal and Spain. Ann Oncol 2012;23(8):2006-2015.

45. Gomes B, Calanzani N, Gysels M, Hall S, Higginson I. Heterogeneity and changes in preferences for dying at home: a systematic review. BMC Palliat Care 2013;12(1):7.

46. Murtagh FEM, Bausewein C, Petkova H, Sleeman KE, Dodd RH, Gysels M, Johnston B, Murray S, Banerjee S, Shipman C, Hansford P, Wakefield D, Gomes B, Higginson IJ. Understanding place of death for patients with non malignant conditions: a systematic literature review. Final report. NIHR Service Delivery and Organisation Programme 2012.

47. Davies E, Higginson I, (editors). The solid facts: Palliative care. Geneva: World Health Organisation 2004.

48. Department of Health. End of Life Care Strategy: Quality Markers and measures for end of life care. 2009. Available: http://webarchive.nationalarchives.gov.uk/20130107105354/http://www.dh.gov.uk/en/PublicationsandStatistics/Publications/PublicationsPolicyAndGuidance/DH_101681. Accessed 19th December 2014.

49. Teno JM, Gozalo PL, Bynum JPW, Leland NE, Miller SC, Morden NE, Scupp T, Goodman DC, Mor V. Change in end-of-life care for Medicare beneficiaries: site of death, place of care, and health care transitions in 2000, 2005, and 2009. JAMA 2013;309(5):470-477.

50. Earle CC, Park ER, Lai B, Weeks JC, Ayanian JZ, Block S. Identifying potential indicators of the quality of end-of-life cancer care from administrative data. J Clin Oncol 2003;21(6):1133-1138.

51. Grunfeld E, Urquhart R, Mykhalovskiy E, Folkes A, Johnston G, Burge FI, Earle CC, Dent S. Toward population-based indicators of quality end-of-life care: testing stakeholder agreement. Cancer 2008;112(10):2301-2308.

52. Association of Public Health Observatories (APHO), NHS Institute for Innovation and Improvement. The Good Indicators Guide: Understanding how to use and choose indicators. http://www.apho.org.uk/resource/view.aspx?RID=44584. Accessed 19th December 2014; 2006.

53. Woitha K, Van Beek K, Ahmed N, Jaspers B, Mollard JM, Ahmedzai SH, Hasselaar J, Menten J, Vissers K, Engels Y. Validation of quality indicators for the organization of palliative care: a modified RAND Delphi study in seven European countries (the Europall project). Palliat Med 2014;28(2):121-129.

54. van der Ploeg E, Depla MFI, Shekelle P, Rigter H, Mackenbach JP. Developing quality indicators for general practice care for vulnerable elders; transfer from US to The Netherlands. Quality & Safety in Health Care 2008;17(4):291-295.

55. Marshall MN, Shekelle PG, McGlynn EA, Campbell S, Brook RH, Roland MO. Can health care quality indicators be transferred between countries? Qual Saf Health Care 2003;12(1):8-12.

56. de Koning J, Smulders A, Klazinga N. Appraisal of Indicators through Research and Evaluation (AIRE). http://www.ha-ring.nl/download/literatuur/Handleiding%20Indicatorenontwikkeling%20CBO.pdf. Accessed 19th December 2014; 2007.

57. Berg M, Meijerink Y, Gras M, Goossensen A, Schellekens W, Haeck J, Kallewaard M, Kingma H. Feasibility first: developing public performance indicators on patient safety and clinical effectiveness for Dutch hospitals. Health Policy 2005;75(1):59-73.

58. Wollersheim H, Hermens R, Hulscher M, Braspenning J, Ouwens M, Schouten J, Marres H, Dijkstra R, Grol R. Clinical indicators: development and applications. Neth J Med 2007;65(1):15-22.

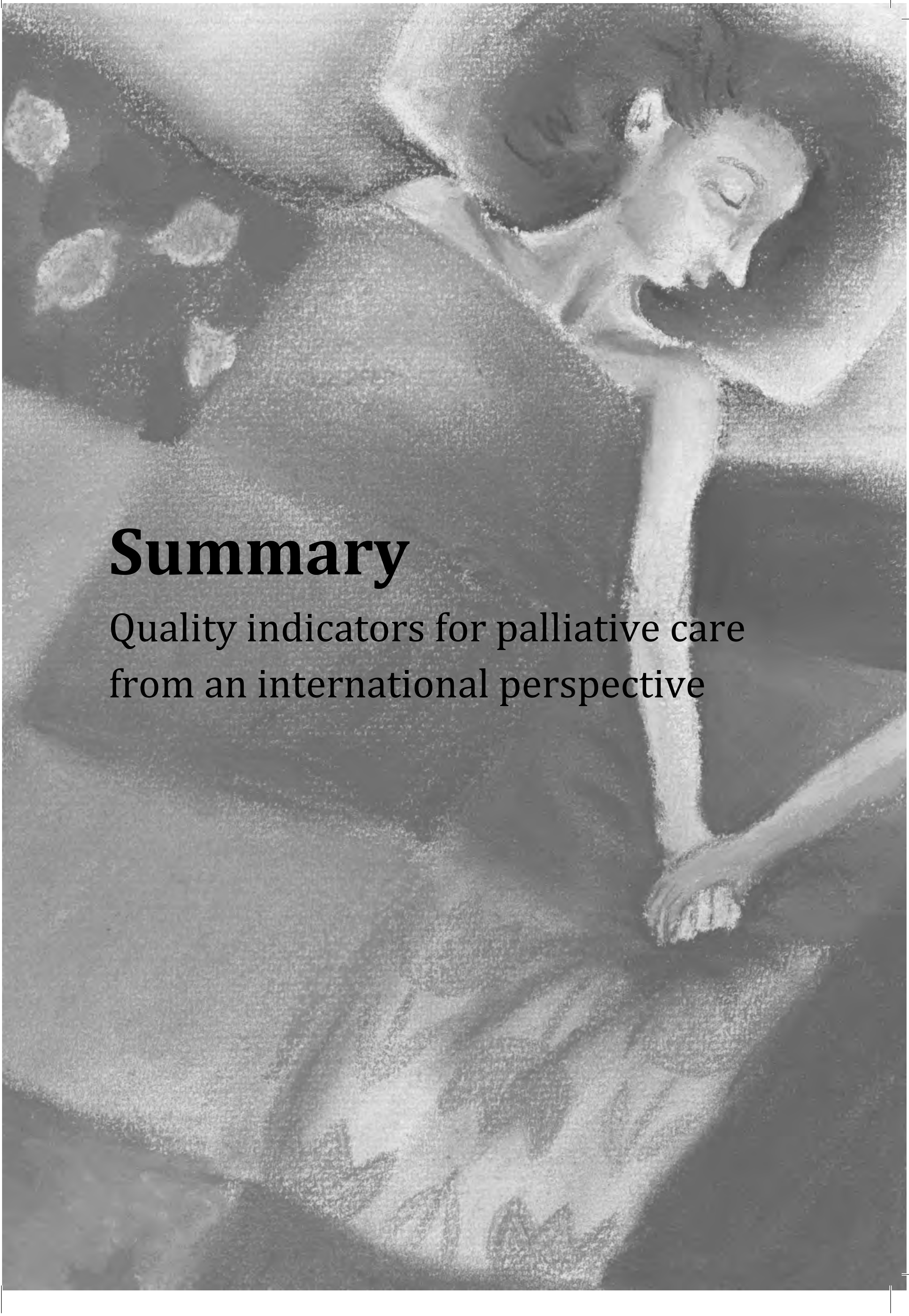
59. Broad JB, Gott M, Kim H, Boyd M, Chen H, Connolly MJ. Where do people die? An international comparison of the percentage of deaths occurring in hospital and residential aged care settings in 45 populations, using published and available statistics. Int J Public Health 2013;58(2):257-267.

60. Mpinga EK, Pennec S, Gomes B, Cohen J, Higginson IJ, Wilson D, Rapin CH. First international symposium on places of death: an agenda for the 21st century. J Palliat Care 2006;22(4):293-296.

61. Van den Block L, Onwuteaka-Philipsen B, Meeussen K, Donker G, Giusti F, Miccinesi G, Van Casteren V, Alonso T, Zurriaga O, Deliens L. Nationwide continuous monitoring of end-of-life care via representative networks of general practitioners in Europe. BMC Fam Pract 2013;14(1):73.

62. 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.

63. Grol R, Wensing M. Implementatie: Effectieve verbetering van de patiëntenzorg [Implementation: Effective improvement of patient care]. 4 ed. Amsterdam: Reed Business; 2011.



# Summary

## Quality indicators for palliative care from an international perspective

It is crystal clear that patients deserve good quality palliative care. Therefore, evaluating quality of care is essential. Quality indicators can be measured to provide more insights into the quality of care provided. Quality indicators are measurable aspects concerning the structure, processes, and outcomes of care. They can highlight both aspects of care that are already functioning well and areas where care can still be improved. In palliative care too, such quality indicators can be useful. Palliative care focuses on patients with an incurable disease and their family members. Because of the ageing of our society, the number of people living with a chronic, eventually fatal condition is rising, resulting in an increasing number of people who will need palliative care. Palliative care is a complex type of care, implying a multidisciplinary and holistic approach. This care focuses not just on an optimal control of physical symptoms, but also pays attention to psychological, social, and spiritual aspects of care.

A systematic literature review of quality indicators for palliative care in 2007 revealed eight indicator sets that had been developed for palliative care, containing a total of 142 quality indicators. In recent years, the interest in quality indicators for palliative care has been growing in policy, practice, and research. Therefore it was expected that new quality indicators for palliative care would have been developed since 2007.

Hence, a logical first step in this PhD research project was to update the existing systematic review from 2007. This update, which can be found in **Chapter 2**, indeed revealed nine new indicator sets, which brings the total number of quality indicators for palliative care to 326 indicators. Physical aspects of care (e.g. measuring and treating pain) and the care delivery structure and processes (e.g. communication with patients and family) received more attention than social, cultural, and spiritual aspects of care, both in the updated review and the original one. In the update, indicators concerning care processes (e.g. documenting the actual care delivered to the patient) were still more prevalent than indicators focusing on outcomes and structures. There are substantial differences between indicator sets in the level of detail of the description of the development process and the testing of the quality indicators in practice. Yet properly developed indicators that have been tested in practice are needed for optimal improvement of care.

Next, Chapters 3 to 6 of this dissertation examine a selection of five existing quality indicators in detail and test them on existing research data. Measuring quality indicators must not be a burden for patients, family or caregivers. Using data collected routinely by caregivers or using existing research data overcomes this barrier and offers the additional advantage that minimal extra costs and effort are needed. This is the reason why this PhD research project used existing data.

**Chapters 3 and 4** make use of data from the "EURO SENTI-MELC" study, a retrospective mortality follow-back study, concerning care at the end of life in four countries: Belgium, the Netherlands, Italy, and Spain. Data were collected by representative general practitioner (GP) networks (so-called sentinel networks) from 2009 to 2011. GPs filled in a standardized registration form about recently deceased patients in their practice. This dissertation only included patients whose death was expected by the GP.

**Chapter 3** focuses on two indicators concerning the place of death: "the percentage of patients dying at home"[1] and "the percentage of patients who died in the place of their preference".[2] The indicator scores were calculated for patients mainly residing at home in the last month before death. The percentage of home deaths was 35.3% for Belgium (N=1036), 49.1% for Italy (N=1639), 51.3% for Spain (N=565), and 50.6% for the Netherlands (N=512). None of the four countries reached the performance standard of 95% formulated by the original indicator set,[1] which was developed for palliative home care. However, not all patients in the study population of Chapter 3 received palliative home care.
The preferred place of death was known by the GP in 29.7% of patients in Italy, 33.1% in Spain, 42.5% in Belgium, and 60.4% in the Netherlands. Of these patients, 67.8% died at the place of their preference in Italy (N=485), 72.6% in Belgium (N=437), 75.4% in the Netherlands (N=303), and 86.0% in Spain (N=165). So far, no performance standard has been formulated for this indicator, as the developers of this set[2] indicated that a "relative" best practice norm should be derived from the best scoring care providers in practice (e.g. the lower limit of the best scoring quartile of care providers).
Chapter 3 also shows that some care characteristics are related to quality indicators concerning dying at home and at the place of preference (in patients whose preference was known). Patients were more likely to die at home (in all four countries) and more likely to die at their place of preference (significant in Belgium, the Netherlands, and Italy) when the GP provided palliative care. Patients were less likely to die at home (in Belgium and Spain) when cure was still an important care goal in the last two to four weeks of life, and were also less likely to die at home when life prolongation was still an important care goal at that time (in Italy and Spain).

**Chapter 4** goes into depth on quality indicators concerning hospitalizations in the last month of life: “the percentage of time spent in hospital”[1] in the last month of life, and “the proportion of patients with more than one hospitalization in the last 30 days of life”.[3] As one of the indicators was originally developed for cancer patients[3] and the other one for home palliative care,[1] only cancer patients mainly residing at home in the last month of life were included. The analyses show that 14.1% of time in the last month of life was spent in hospital in the Netherlands (N=310), 17.7% in Spain (N=224), 22.2% in Italy (N=764), and 24.6% in Belgium (N=500). None of the four countries met the performance standard, which states that less of 10% of time should be spent in hospital. The percentage of patients who were hospitalized more than once in the last month of life was 0.6% in the Netherlands (N=310), 3.1% in Italy (N=764), 4.0% in Spain (N=224), and 5.4% in Belgium (N=500). This means that the Netherlands and Italy meet the performance standard, which states that less than 4% of patients should be hospitalized more than once in the last month of life.
The analyses of Chapter 4 also show that less time was spent in hospital in the last month of life (in all four countries) and fewer patients were hospitalized more than once in the last month of life (only significant in Italy) in the group of patients receiving palliative care from their GP compared with patients who did not receive palliative care from their GP. The differences in indicator scores between the four countries seem to reflect specific differences in the organization of care in general and palliative care in particular. One of these differences is the role of the GP. In the Netherlands for example, GPs have substantial responsibility, both in healthcare in general, where they fulfill a gatekeeper function controlling access to second-line care, and in palliative care. Probably, this is one of the reasons why hospitalizations are shorter and patients are hospitalized less frequently in the Netherlands.

Chapters 3 and 4 also reveal that existing data collected by GP networks are suitable for calculating quality indicator scores concerning dying at home, and the frequency and duration of hospitalizations in the last month of life, since the number of missing values was low. Discussing the preferred place of death is still a challenge for GPs: only in 30% to 60% of cases did the GP know the place of preference, which impeded a valid calculation of this quality indicator.

In **Chapters 5 and 6,** the quality indicator “the percentage of relatives who indicate that the patient died peacefully”[2] was explored with the help of two datasets. **Chapter 5** is based on data from the “Dutch End of Life in Dementia” study, a study concerning care at the end of life for residents with dementia (N=233) in 28 nursing homes and

four care homes in the Netherlands. **Chapter 6** worked with data from the “Dying Well with Dementia in Flanders” study, which took place in 69 nursing homes in Flanders (Belgium) and concerned deceased residents with dementia (N=92).
Quality indicator scores found in the two chapters are comparable: in the Netherlands, 56.2% of the relatives indicated that the resident died peacefully (Chapter 5), while the percentage in Flanders was 54.4% (Chapter 6). The data for the Netherlands were also investigated to see how this indicator score differed between different care facilities. Quality indicator scores varied between 17% and 80%, with most care facilities having a score between 30% and 64% (Chapter 5).

Furthermore, an analysis was performed to see whether the indicator “the percentage of relatives who indicate that the patient died peacefully” is related to differences in the care provided, besides revealing differences between residents. After all, quality indicators are intended to reflect differences in the care delivered. Concerning characteristics of the residents, it was shown that when the relatives found that the resident had an optimistic attitude, this was related to dying more peacefully (Chapter 5). In addition, when relatives found that there was less physical distress in the last week of life, or less psychological distress in the last week or last month of life, this was related to dying more peacefully (Chapter 6). As regards the characteristics of the care provided and of the care facilities in relation to the “dying peacefully” quality indicator, Chapter 5 demonstrated for example that residents were more likely to die peacefully if relatives judged that enough nurses were available.

The last chapter **(Chapter 7)** summarizes the most important results of the previous chapters and reflects on the findings and methodological aspects in a broader context, resulting in some recommendations. In brief, these recommendations include the following. Since a lot of quality indicators for palliative care have already been developed, it is recommended to use and further develop these existing quality indicators in clinical practice and quality research. Ideally, these indicators should be tested further in practice and adjusted where needed, and be optimized in this way. Furthermore, international organizations should promote the use of quality indicators and the definition of an international minimum set of quality indicators. Using this minimum indicator set on a national and international level could contribute to the transparency of the quality of palliative care. In addition, policy-makers and researchers need to investigate ways to calculate quality indicator scores with routinely collected data. This dissertation has shown that data collected by GP sentinel networks can be used to calculate quality indicator scores.

Last but not least, it is important for policy-makers and researchers to realize that measuring quality indicator scores is just a first step toward actually improving the quality of care. Caregivers can use quality indicators scores to verify which aspects of care could be enhanced. Ideally, this should lead to strategies to improve this suboptimal quality of care.

## REFERENCES

1. Peruselli C, Marinari M, Brivio B, Castagnini G, Cavana M, Centrone G, Magni C, Merlini M, Scaccabarozzi GL, Paci E. Evaluating a home palliative care service: development of indicators for a continuous quality improvement program. J Palliat Care 1997;13(3):34-42.
2. Claessen SJJ, Francke AL, Belarbi HE, Pasman HR, van der Putten MJA, Deliens L. 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.
3. Earle CC, Neville BA, Landrum MB, Souza JM, Weeks JC, Block SD, Grunfeld E, Ayanian JZ. Evaluating claims-based indicators of the intensity of end-of-life cancer care. Int J Qual Health Care 2005;17(6):505-509.

# Samenvatting

## Kwaliteitsindicatoren voor palliatieve zorg vanuit internationaal perspectief

Dat patiënten zorg van goede kwaliteit verdienen, staat als een paal boven water. Evaluatie van de kwaliteit van zorg is daarom onontbeerlijk. Om inzicht te krijgen in de kwaliteit van zorg kunnen kwaliteitsindicatoren gemeten worden. Kwaliteitsindicatoren zijn meetbare aspecten over structuur, processen of uitkomsten van zorg. Ze kunnen aspecten van zorg belichten waar het reeds goed gaat, maar ook waar zorg juist nog beter kan.

Ook bij palliatieve zorg is het gebruik van dergelijke kwaliteitsindicatoren nuttig. Palliatieve zorg spitst zich toe op patiënten met een ongeneeslijke aandoening en hun familieleden. Door de vergijzing van de bevolking neemt het aantal mensen dat kampt met een chronische, uiteindelijk fatale aandoening toe, waardoor ook het aantal mensen met een behoefte aan palliatieve zorg stijgt. Palliatieve zorg is complexe zorg en impliceert een multidisciplinaire en holistische aanpak. Deze zorg richt zich niet alleen op optimale controle van fysieke symptomen, maar ook op zorgbehoeften van psychologische, sociale en spirituele aard.

Uit een systematische literatuurreview naar kwaliteitsindicatoren voor palliatieve zorg uit 2007 was bekend dat er al acht indicatorensets, goed voor 142 kwaliteitsindicatoren, voor palliatieve zorg waren ontwikkeld. Omdat de laatste paar jaar de interesse voor kwaliteitsindicatoren voor palliatieve zorg in beleid, praktijk en onderzoek is toegenomen, was de verwachting dat er inmiddels nieuwe kwaliteitsindicatoren voor palliatieve zorg beschikbaar zouden zijn.

Een logische eerste stap binnen dit promotieonderzoek was daarom het updaten van de bestaande systematische review uit 2007. Deze update, beschreven in **Hoofdstuk 2**, vond inderdaad negen nieuwe indicatorensets, wat het totale aantal kwaliteitsindicatoren voor palliatieve zorg op 326 indicatoren brengt. Fysieke aspecten van zorg (bijvoorbeeld pijnmeting en -bestrijding) en structurele en procesmatige aspecten van zorg (bijvoorbeeld communicatie met patiënten en familie) kwamen net als in de review uit 2007 nog steeds veel vaker aan bod in de indicatorensets dan sociale, culturele en spirituele zorgaspecten. Indicatoren over zorgprocessen (bijvoorbeeld het documenteren van de zorg) kwamen ook in de update veel vaker voor dan uitkomstindicatoren en structuurindicatoren. De mate van detail waarin het ontwikkelingsproces en het testen van de indicatoren in de praktijk is beschreven, verschilt sterk tussen indicatorensets onderling. Echter, voor een optimale verbetering van de zorg, zijn goed onderbouwde en in de praktijk geteste indicatoren nodig.

In Hoofdstukken 3 tot en met 6 van deze dissertatie wordt een selectie van vijf bestaande kwaliteitsindicatoren dan ook in detail bekeken en getest op bestaande gegevensbestanden. Het meten van kwaliteitsindicatoren mag geen te grote last vormen voor patiënt, familie of zorgverlener. Gebruik maken van gegevens die routinematig door zorgverleners worden geregistreerd of van bestaande onderzoeksgegevens, omzeilt dit euvel en heeft als bijkomend voordeel dat er weinig extra kosten en inspanningen vereist zijn. Dit is een reden waarom in dit promotieonderzoek bestaande gegevens zijn gebruikt.

In **Hoofdstuk 3 en 4** zijn gegevens gebruikt uit de "EURO SENTI-MELC" studie, een retrospectief mortaliteitsonderzoek dat zorg aan het levenseinde bestudeert in vier landen: België, Nederland, Italië en Spanje. Deze gegevens zijn verzameld door representatieve huisartsennetwerken (zogenaamde peilstations) van 2009 tot en met 2011. Op een gestandaardiseerd registratieformulier registreerden huisartsen informatie over de recent overleden patiënten uit hun praktijk. In deze dissertatie zijn enkel de gegevens van patiënten gebruikt van wie het overlijden verwacht was volgens de inschatting van de huisarts.

**Hoofdstuk 3** beschrijft de indicatorscores voor twee indicatoren over plaats van overlijden "het percentage patiënten dat thuis is overleden"[1] en "het percentage patiënten dat op de plaats van voorkeur is overleden".[2] De indicatorscores zijn berekend voor patiënten die hoofdzakelijk thuis verbleven in de laatste maand voor overlijden. Het percentage thuis overledenen bedroeg 35.3% voor België (N=1036), 49.1% voor Italië (N=1639), 51.3% voor Spanje (N=565) en 50.6% voor Nederland (N=512). Geen van de vier landen haalde de streefnorm van 95%, uit de achterliggende indicatorenset[1] die oorspronkelijk ontwikkeld was voor palliatieve thuiszorg. In de onderzochte groep uit Hoofdstuk 3 kregen echter niet alle patiënten palliatieve thuiszorg.

De voorkeursplaats van overlijden was gekend bij de huisarts voor 29.7% van de patiënten in Italië, 33.1% in Spanje, 42.5% in België en 60.4% in Nederland. Van deze patiënten overleed 67.8% op de plaats van voorkeur in Italië (N=485), 72.6% in België (N=437), 75.4% in Nederland (N=303), en 86.0% in Spanje (N=165). Tot dusver werd er geen streefnorm geformuleerd voor deze indicator, gezien door de ontwikkelaars[2] van deze indicatorenset bepaald was dat een "relatieve" streefnorm afgeleid moest worden van de best presterende zorgaanbieders in de praktijk (bijvoorbeeld de ondergrens van het best scorende kwartiel van zorgaanbieders).

Hoofdstuk 3 laat ook zien dat een aantal zorgkenmerken gerelateerd was aan de kwaliteitsindicatoren over thuis overlijden en over overlijden op de plaats van voorkeur (bij patiënten van wie de voorkeur bekend was). Zo bleek dat patiënten aan wie de huisarts palliatieve zorg verleende, een hogere kans hadden om thuis te overlijden (in alle vier de landen) en om te overlijden op plaats van voorkeur (significant in België, Nederland en Italië). Wanneer genezing nog een belangrijk behandeldoel vormde in de laatste twee tot vier weken voor overlijden, was de kans om thuis te sterven kleiner (in België en Spanje), net zoals de kans kleiner was om thuis te sterven als levensverlenging nog een belangrijk behandeldoel was (in Italië en Spanje).

**Hoofdstuk 4** gaat in op kwaliteitsindicatoren rond ziekenhuisopnames in de laatste levensmaand: "het percentage tijd doorgebracht in het ziekenhuis"[1] in de laatste levensmaand, en "het percentage patiënten met meer dan één ziekenhuisopname in de laatste levensmaand".[3] Gezien een van de indicatoren ontwikkeld was voor een populatie kankerpatiënten[3] en de andere voor palliatieve thuiszorg[1], selecteerden we enkel de kankerpatiënten die voornamelijk thuis verbleven in de laatste levensmaand. Uit de analyses bleek dat 14.1% van de tijd werd doorgebracht in het ziekenhuis in de laatste levensmaand in Nederland (N=310), 17.7% in Spanje (N=224), 22.2% in Italië (N=764), en 24.6% in België (N=500). De streefnorm van minder dan 10% van de tijd doorgebracht in het ziekenhuis werd in geen van de vier landen gehaald. Het percentage patiënten dat meermaals werd opgenomen in het ziekenhuis in de laatste levensmaand, bedroeg 0.6% in Nederland (N=310), 3.1% in Italië (N=764), 4.0% in Spanje (N=224) en 5.4% in België (N=500). Dit betekent dat Nederland en Italië de streefnorm halen van minder dan 4% patiënten die meermaals werden opgenomen in het ziekenhuis in de laatste levensmaand.
In de analyses van Hoofdstuk 4 viel ook op dat er minder tijd in het ziekenhuis werd doorgebracht in de laatste levensmaand (in alle landen) en minder patiënten meermaals zijn gehospitaliseerd in de laatste levensmaand in de groep die palliatieve zorg kreeg van de huisarts (enkel significant in Italië). De verschillen in indicatorscores tussen landen lijken specifieke verschillen in de organisatie van zorg en palliatieve zorg te reflecteren. Een van deze verschillen is de rol van de huisarts. In Nederland bijvoorbeeld hebben huisartsen een grote verantwoordelijkheid, zowel in het algemeen, waar ze een poortwachtersfunctie hebben tot de toegang naar tweedelijnszorg zoals ziekenhuiszorg, als in de palliatieve zorgverlening. Mogelijk is

dit een van de redenen waarom in Nederland hospitalisaties korter zijn en patiënten ook minder frequent worden gehospitaliseerd.

Uit Hoofdstuk 3 en 4 blijkt ook dat bestaande registraties van huisartsennetwerken geschikt zijn om de indicatorscores rond thuis overlijden, de frequentie en de duur van ziekenhuisopnames in de laatste levensmaand te berekenen omdat het aantal missende antwoorden laag was. Het bespreken van de voorkeursplaats van overlijden blijft echter een uitdaging voor huisartsen: slechts in 30% tot 60% van de gevallen had de huisarts de voorkeursplaats van de patiënt geregistreerd, wat een valide berekening van de betreffende kwaliteitsindicator belemmerde.

In **Hoofdstuk 5 en 6** wordt de kwaliteitsindicator "het percentage directe naasten dat aangeeft dat de patiënt vredig is gestorven"[2] onder de loep genomen aan de hand van twee verschillende gegevensbestanden. In **Hoofdstuk 5** gebeurde dit aan de hand van bestaande gegevens uit de "Dutch End of Life in Dementia" studie, over zorg aan het levenseinde van bewoners met dementie (N=233) in 28 verpleeghuizen en vier verzorgingshuizen in Nederland.
**Hoofdstuk 6** is gebaseerd op de "Dying Well with Dementia in Flanders" studie, uitgevoerd in 69 Vlaamse rusthuizen bij overleden bewoners met dementie (N=92).
De gevonden indicatorscores in de beide hoofdstukken zijn zeer vergelijkbaar: in Nederland gaf 56.2% van de directe naasten aan dat de bewoner vredig was overleden (Hoofdstuk 5), in Vlaanderen was deze 54.4% (Hoofdstuk 6). In Nederland werd ook nagegaan in hoeverre deze indicatorscore verschilde tussen zorginstellingen. Hieruit bleek dat indicatorscores varieerden tussen 17% en 80%, waarbij de meeste instellingen tussen 30% en 64% scoorden (Hoofdstuk 5).

Verder werd ook nagegaan of de indicator "het percentage directe naasten dat aangeeft dat de patiënt vredig is gestorven" naast verschillen tussen de bewoners, ook effectief gerelateerd is aan verschillen in de verleende zorg. Kwaliteitsindicatoren dienen namelijk verschillen in zorg te reflecteren.
Voor wat betreft de kenmerken van de bewoners, bleek dat wanneer de familie vond dat de bewoner een optimistische levenshouding had, dit gerelateerd was aan vrediger sterven van de bewoner (Hoofdstuk 5). Verder bleek ook dat wanneer de familie vond dat er minder lichamelijke ongemakken waren in de laatste levensweek, of minder psychologische distress in de laatste week of maand voor overlijden vaststelde, dit gerelateerd was aan vrediger sterven (Hoofdstuk 6). Qua zorgkenmerken en kenmerken van de zorginstellingen die gerelateerd zijn aan de

kwaliteitsindicator rond vredig sterven, bleek bijvoorbeeld dat bewoners een hogere kans hadden om vredig te sterven, wanneer de familie oordeelde dat er voldoende verpleegkundig personeel aanwezig was (Hoofdstuk 5).

Het laatste hoofdstuk **(Hoofdstuk 7)** vat de belangrijkste resultaten van de voorgaande hoofdstukken samen en reflecteert over de bevindingen en methodologische aspecten in een bredere context, wat uiteindelijk resulteert in een aantal aanbevelingen.

Kort samengevat komen deze aanbevelingen op het volgende neer. Omdat al heel wat kwaliteitsindicatoren voor palliatieve zorg ontwikkeld zijn, wordt aanbevolen om waar mogelijk op deze bestaande indicatoren in de praktijk en in kwaliteitsonderzoek verder te bouwen. Idealiter zou men deze indicatoren verder kunnen testen in de praktijk, waar nodig aanpassen en zo deze indicatoren optimaliseren. Verder zouden internationale organisaties het gebruik van kwaliteitsindicatoren en het opstellen van een internationale minimale indicatorenset moeten promoten. Gebruik van een minimale indicatorenset kan op nationaal en internationaal niveau bijdragen tot de transparantie van de kwaliteit van palliatieve zorg. Daarbij moeten beleidsmakers en onderzoekers ook zoeken naar manieren om kwaliteitsindicatoren te meten met routinematig verzamelde gegevens. In deze dissertatie is gebleken dat bijvoorbeeld huisartsennetwerken (peilstations) bruikbare registraties hebben op basis waarvan scores op kwaliteitsindicatoren berekend kunnen worden.

En “last but not least”, is het belangrijk dat beleidsmakers en onderzoekers zich realiseren dat het meten van indicatorscores slechts een eerste stap is in het werkelijk verbeteren van de kwaliteit van zorg. Zorgverleners kunnen aan de hand van scores op kwaliteitsindicatoren nagaan waar de zorg nog beter kan. Idealiter volgen hieruit dan strategieën om deze suboptimale kwaliteit van zorg te verbeteren.

## REFERENTIES

1. Peruselli C, Marinari M, Brivio B, Castagnini G, Cavana M, Centrone G, Magni C, Merlini M, Scaccabarozzi GL, Paci E. Evaluating a home palliative care service: development of indicators for a continuous quality improvement program. J Palliat Care 1997;13(3):34-42.
2. Claessen SJJ, Francke AL, Belarbi HE, Pasman HR, van der Putten MJA, Deliens L. 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.
3. Earle CC, Neville BA, Landrum MB, Souza JM, Weeks JC, Block SD, Grunfeld E, Ayanian JZ. Evaluating claims-based indicators of the intensity of end-of-life cancer care. Int J Qual Health Care 2005;17(6):505-509.

# About the author
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# ABOUT THE AUTHOR

Maaike De Roo was born July 20, 1986 in Ghent, Belgium. After studying Greek-Mathematics in high school, Sint-Bavohumaniora in Ghent, she started studying Medicine at Ghent University in 2004. During her medical studies, she was involved in the research project “Development of a symptom scale for the frail older patient at the end of life” under the supervision of prof. Nele Van Den Noortgate and dr. Ruth Piers. End of June 2011, she obtained her medical degree and moved to Amsterdam. In July 2011 she started working as an early-stage researcher on the EURO IMPACT project (see “About EURO IMPACT”) at the EMGO+ Institute for Health and Care Research, Department of Public and Occupational Health, VU University Medical Center, Amsterdam. Within the EURO IMPACT project (European Intersectorial and Multi-disciplinary Palliative Care Research Training) Maaike wrote her Phd-thesis based on a work package concerning quality indicators for palliative care, under the supervision of prof. Anneke Francke and prof. Luc Deliens. During the project, she was also seconded to the ISPO (Istituto per lo Studio e la Prevenzione Oncologica) in Florence, Italy for 6 months, to work on the EURO-SENTIMELC data under the supervision of prof. Guido Miccinesi.
In September 2014, Maaike started working as a trainee in Internal Medicine, in the Orbis Medisch Centrum in Sittard-Geleen, the Netherlands.

# ABOUT EURO IMPACT

**EURO IMPACT, Euro**pean **I**ntersectorial and **M**ultidisciplinary **Pa**lliative **C**are Research **T**raining is an EU funded Marie Curie Initial Training Network with a specific focus on training early-stage researchers (European Union Seventh Framework Programme FP7/2007-2013, under grant agreement n° [264697]). It aims to develop a multidisciplinary, multi-professional and inter-sectorial educational and research training framework for palliative care research in Europe. EURO IMPACT is coordinated by Prof Luc Deliens and Prof Lieve Van den Block of the End-of-Life Care Research Group, Ghent University & Vrije Universiteit Brussel, Brussels, Belgium.
Other collaborators involved are: Zeger De Groote, Sarah Brearley, Augusto Caraceni, Joachim Cohen, Anneke Francke, Richard Harding, Irene Higginson, Stein Kaasa, Karen Linden, Guido Miccinesi, Bregje Onwuteaka-Philipsen, Koen Pardon, Roeline Pasman, Sophie Pautex, Sheila Payne. For the affiliations of the collaborators, see the EURO IMPACT website (http://euro-impact.eu/).

Besides the focus on training, another goal was to finalise the scientific output into a PhD-dissertation. Since the trajectory of the researchers only lasted for 3 years, including all obligatory trainings mentioned below, existing data that had been gathered previously by the EURO IMPACT partners across Europe were used for the PhD-dissertation.

During her EURO IMPACT trajectory, Maaike participated in the following trainings:

- "Ethics in Palliative Care"; Networkwide training EURO IMPACT, Brussels, 1 day, July 2011
- "Multidisciplinary research in Palliative Care"; Networkwide training EURO IMPACT, Brussels, 1 day, July 2011
- "Palliative care research – theoretical, practical, ethical and methodological aspects"; Norwegian University of Science and Technology Trondheim, 1 week, September 2011
- "International Comparison of Health Care Systems"; The Netherlands Institute for Health Sciences (NIVEL) Utrecht, Rotterdam, 1 week, November 2011
- "Research Methods and Statistics in Palliative Care"; King's College London, Cicely Saunders Institute, London, 2 weeks, January 2012

- “Psychosocial, Cultural, Ethical and Spiritual Issues in Palliative Care”; King’s College London, Cicely Saunders Institute, London, 2 weeks, April 2012
- “Palliative Care: History, concepts and debates” [“The evidence base and the impact on policy”, “Global history and development of hospice and palliative care”, “Concepts, models and debates in supportive and end of life care” and “Assessing need and developing service evaluation”]; e-learning International Observatory on End of Life Care, Lancaster University, 8 weeks, April-June 2012
- “PhD in Palliative Care – Summer Academy 2012”, Summer School PhD in Palliative Care, International Observatory on End of Life Care, Lancaster University, 2 weeks, June 2012
- “Training societal dissemination: disseminating findings to other researchers, practitioners, policymakers, and users of our services; translation of results into useful and usable information for practice and policy makers”; Networkwide training EURO IMPACT, Milan, 1 day, March 2013
- “Media training: communicating about delicate and ethical subjects and situations”; Networkwide training EURO IMPACT, Milan, 1 day, March 2013
- “Presenting in English”; Taalcentrum VU University, Amsterdam, 6 days, April-May 2013
- “The impact of research on health care policy and clinical practice: what else do we need besides scientific excellence?”, Networkwide training EURO IMPACT, Prague, June 2013

Maaike was seconded to the ISPO (Istituto per lo Studio e la Prevenzione Oncologica) in Florence, Italy for 6 months (September 2012 - February 2013).

# LIST OF PUBLISHED OR ACCEPTED PAPERS AND ABSTRACTS

## Articles in international peer-reviewed journals

De Roo ML, Francke AL, Van den Block L, Donker GA, Lozano Alonso JE, Miccinesi G, Moreels S, Onwuteaka-Philipsen BD, Salvetti A, Deliens L, on behalf of EURO IMPACT. Hospitalizations of cancer patients in the last month of life: quality indicator scores reveal large variation between four European countries in a mortality follow-back study. BMC Palliative Care 2014;13:54.

De Roo ML, Miccinesi G, Onwuteaka-Philipsen BD, Van Den Noortgate N, Van den Block L, Bonacchi A, Donker GA, Lozano Alonso JE, Moreels S, Deliens L, Francke AL, on behalf of EURO IMPACT. Actual and Preferred Place of Death of Home-Dwelling Patients in Four European Countries: Making Sense of Quality Indicators. PLoS One 2014;9(4):e93762.

De Roo ML, van der Steen JT, Galindo Garre F, Van Den Noortgate N, Onwuteaka-Philipsen BD, Deliens L, Francke AL, on behalf of EURO IMPACT. When do people with dementia die peacefully? An analysis of data collected prospectively in long-term care settings. Palliat Med 2014;28(3):210-219.

De Roo ML, Leemans K, Claessen SJJ, Cohen J, Pasman HR, Deliens L, Francke AL, on behalf of EURO IMPACT. Quality indicators for palliative care: update of a systematic review. J Pain Symptom Manage 2013;46(4):556-572.

## Abstracts presented in international conferences

De Roo ML, Francke AL, Van den Block L, Donker GA, Lozano Alonso JE, Miccinesi G, Moreels S, Onwuteaka-Philipsen BD, Salvetti A, Deliens L, on behalf of EURO IMPACT. Hospitalizations of cancer patients in the last month of life in four European countries: do duration and frequency reflect the quality of care? 8th World Research Congress of the European Association for Palliative Care, Lleida, 5-7 June 2014. Poster presentation.

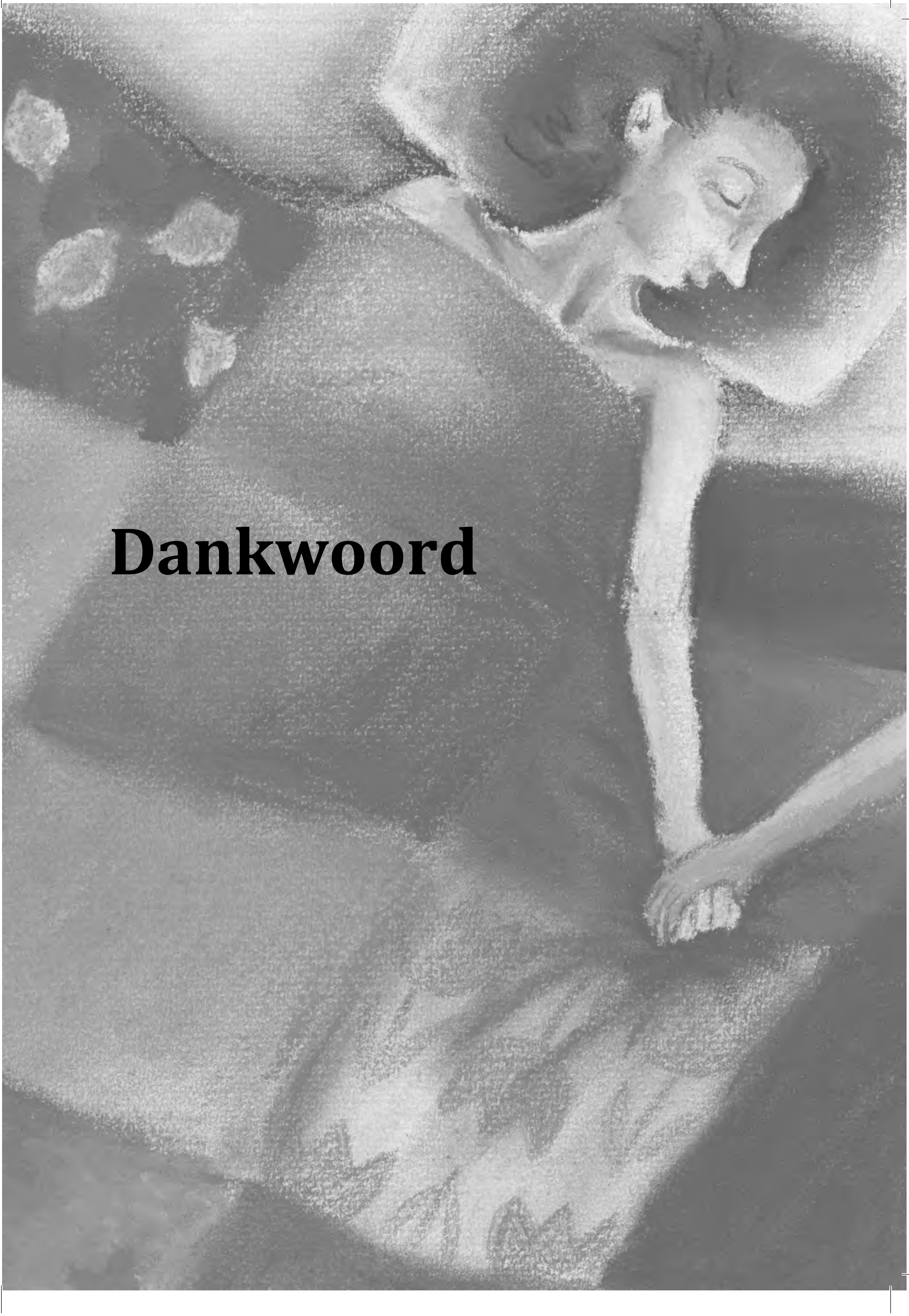
De Roo ML, Miccinesi G, Onwuteaka-Philipsen BD, Van Den Noortgate N, Van den Block L, Bonacchi A, Donker GA, Lozano Alonso JE , Moreels S, Deliens L, Francke AL, on behalf of EURO IMPACT. Actual and preferred place of death as quality indicators for palliative care? 8th World Research Congress of the European Association for Palliative Care, Lleida, 5-7 June 2014. Poster presentation.

De Roo ML, van der Steen JT, Galindo Garre F, Van Den Noortgate N, Onwuteaka-Philipsen BD, Deliens L, Francke AL, on behalf of EURO IMPACT. Dying peacefully in residents with dementia in long-term care facilities: a good quality indicator? 13th Congress of the European Association for Palliative Care, Prague, 30 May - 2 June 2013. Poster presentation.

De Roo ML, Leemans K, Claessen SJJ, Cohen J, Pasman HRW, Deliens L, Francke AL, on behalf of EURO IMPACT. New developments in quality indicators for palliative care. 7th World Research Congress of the European Association for Palliative Care, Trondheim, 7-9 June 2012. Poster presentation.

De Roo M, Van Den Noortgate N, Steeman E, Petrovic M, Piers R. Results of the SATISFIE-study: symptom assessment to improve symptom control for institutionalised elderly. 7th Congress of the European Union Geriatric Medicine Society, Malaga, 28-30 September 2011. Poster presentation.

De Roo M, Uyttersprot A, Piers R, Petrovic M, Velghe A, Van Den Noortgate N, First steps towards validation of a symptom scale for palliative elderly. 6th Research Congress of the European Association for Palliative Care, Glasgow, 10-12 June 2010. Poster presentation.



# Dankwoord

“S’il n’y a plus rien à faire, tout reste à faire”
Thérèse Vanier

Eindelijk is het moment aangebroken. De laatste bladzijden van mijn proefschrift zijn een feit. Het iets meer dan drie jaar hard labeur, inclusief de laatste maanden met de zwaarste loodjes om terug de praktijk in te stappen en tegelijk de laatste zaken af te ronden, is voorbij. Nu krijgt u misschien de indruk dat ik alleen hard heb gewerkt de voorbije jaren, maar dat wil ik graag weerleggen door volgende mensen stuk voor stuk te **BEDANKEN.** Elk op hun manier hebben ze mijn leven heel wat aangenamer gemaakt en mij zo ook ten volle laten genieten van de afgelopen drie jaren. Ze zijn voorbij gevlogen en ik kijk er heel dankbaar op terug.
[For the English-speaking readers, the last three years have been years of hard work for my PhD, but I have enjoyed them to the fullest, because of so many nice people that were there for me. I would like to **THANK** some of them in person below.]

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