Quality indicators to improve palliative care in Flanders, Belgium

Development, evaluation and implementation strategy

Kathleen Leemans

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KATHLEEN LEEMANS

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Promotors: Prof. dr. Luc Deliens
Prof. dr. Joachim Cohen

Co-promotor: Prof. dr. Lieve Van den Block

Examination committee:

President: Prof. dr. Dirk Devroey

Other members: Prof. dr. Wim Distelmans
Prof. dr. Simon Van Belle
Prof. dr. Judith Rietjens
dr. Yvonne Engels

Not everything that can be counted counts

Not everything that counts can be counted

Albert Einstein

Voor opa

CONTENT

Chapters 2-7 are based on the following publications

Chapter 2

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Chapter 3

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Chapter 4

Leemans K, Deliens L, Francke AL, Vander Stichele R, Van den Block L, Cohen J. Quality indicators for palliative care services: Mixed-methods study testing for face validity, feasibility, discriminative power and usefulness. *Palliat Med,* 2014. Epub ahead of print. [SCI impact factor (2013) : 2.845]

Chapter 5

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Chapter 6

Leemans K, Van den Block L, Van der Stichele R, Francke AL, Deliens L, Cohen J. How to successfully implement quality indicators in palliative care services: perceptions of team members about facilitators and barriers for implementation. Submitted.

Chapter 7

Cohen J, Leemans K. How can you prove that you are delivering good care? Monitoring the quality of palliative care using quality indicators. *European Journal of palliative care*, 2014, 21(5):228-31. [No SCI impact factor]

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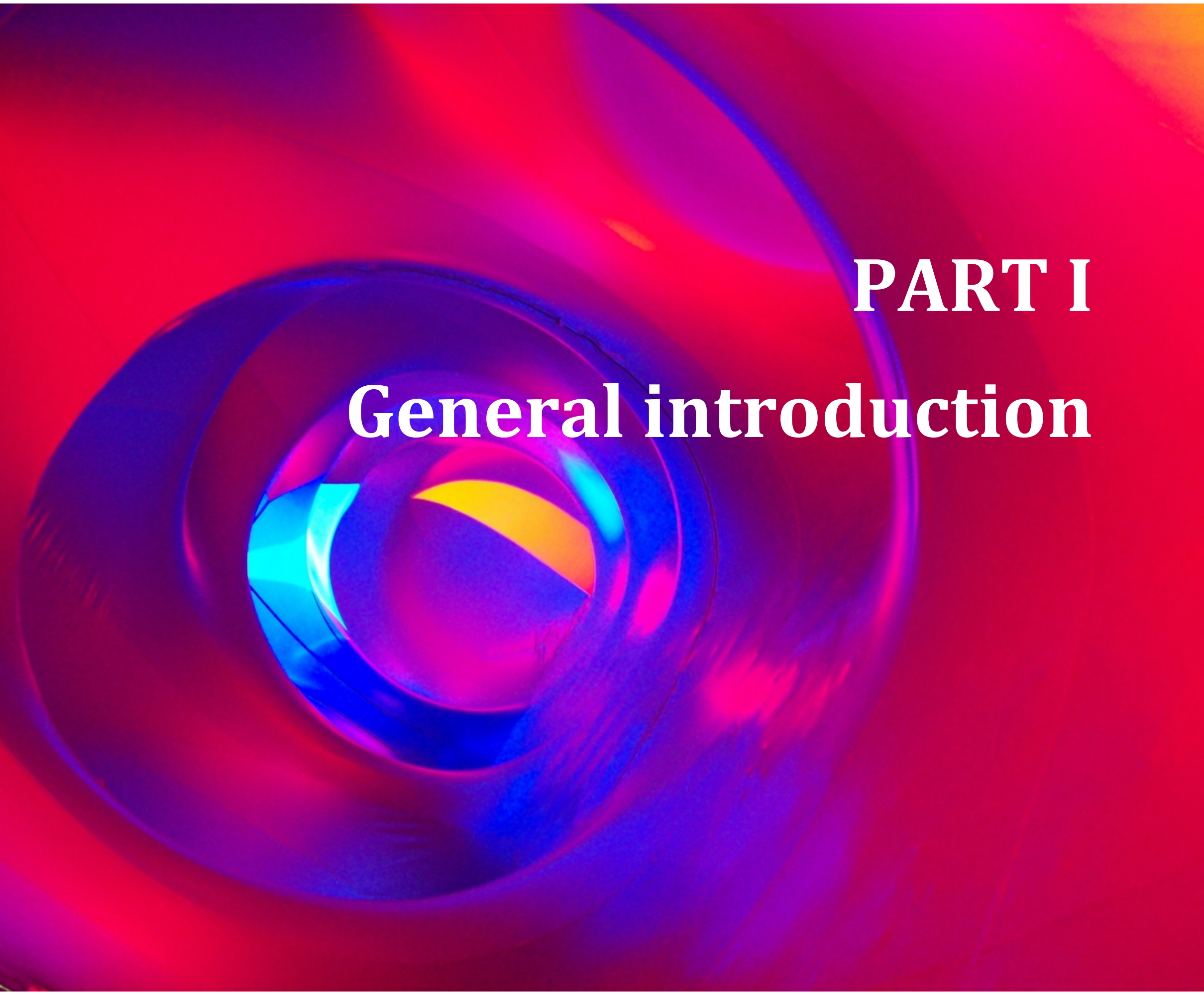


PART I

General introduction

Chapter 1

Introduction and research questions

INTRODUCTION AND RESEARCH QUESTIONS

This thesis focuses on the development of a quality indicator set for specialized palliative care in Flanders, Belgium. The development process of the quality indicators, the results of a feasibility study in palliative care practice, and the development of an implementation strategy are presented in this thesis. This first chapter gives a broad introduction into the concept of quality of care and how quality indicators can be used to improve the care for patients and their families. The chapter also stipulates the necessity of quality indicators in palliative care and the need for indicator validation and identification of conditions for systematic use of quality indicators in national quality measurement. Finally, the chapter describes the methods used in this thesis to develop the quality indicators.

Quality of care

In the past, technological advances in medicine have often obscured the humanity of care (1), not enabling good 'quality of care' for the patient and the family. When medicine can no longer promise an extension of life, patients approaching death and their families should be able to expect that caregivers will provide supportive and humane care. Over the past years, quality of health care has been high on the national agenda in many countries (2;3). Campbell and colleagues (2) define 'quality of care' as the ability for patients to access effective care on an efficient and equitable basis for the optimization of health benefit and well-being of those patients. To reach this goal, the World Health Organization (WHO) suggests that a health system should continuously seek to make improvements in six dimensions of quality: effectiveness, efficiency, accessibility, patient-centeredness, equitability and safety (4). These dimensions are described in table 1.

Insight in quality of care is necessary as research shows that patient care is not always as optimal as possible (5). Scholars such as Campbell but also the WHO recommend caregivers to perform evidence-based medicine in order to strive for optimal care. Hence when operationalizing the concept of 'quality of care', measurement of quality seems indispensable to know what aspects of care need improvement and further investigation. In recent years individual palliative care services and caregivers have applied a profusion of measurement techniques in an attempt to improve the quality of their care. Much of these quality assessments were based on implicit assumptions about how patients and their families define quality of care and what information they value (6). Or caregivers set up dialogues with bereaved family members to discuss their experiences and specific concerns (6;7). Although such methods can detect certain problems and faults in care, they are not a direct or systematic strategy for change and improvement. It remains a challenge to measure quality of care in a systematic, reliable and valid manner so that the results of these measurements can be used to improve care where necessary. Literature points out that quality indicators are the most reliable and valid instruments to meet this challenge (3;8-15).

Table 1: The World Health Organization suggests six dimensions of quality of care (4).

Dimension of quality	Description
Effectiveness	Delivering health care that is adherent to an evidence base and results in improved health outcomes for patients and their community, based on need
Efficiency	Delivering health care in a manner which maximizes resource use and avoids waste of equipment, supplies, ideas and energy
Accessibility	Delivering health care that is timely, geographically reasonable and provided in a setting where skills and resources are appropriate to medical need
Patient-centeredness	Delivering health care which takes into account the patients preferences, aspirations, needs and values
Equitability	Delivering health care which does not vary in quality because of personal characteristics such as gender, race, entity, geographical location or socioeconomic status
Safety	Delivering health care which minimizes risks and harm to patients

In order to measure quality of care, and hence quality of palliative care, quality indicators can be used so that this quality information can be applied for monitoring and improvement of care. Next in this introduction we will discuss what quality indicators are, how to develop them and how to use them in practice. Later in this chapter, the need and purpose of quality indicators within palliative care will be further highlighted.

Quality indicators

Definition

Quality indicators are well-defined and measurable aspects of care, generally expressed in a number or percentage, addressing a specific aspect of care or a related outcome, and expressed at an aggregated level, often the level of care organizations (3;12;13;16). They can help us to understand a system of care, evaluate it and hence improve it (17). An indicator usually consists of a nominator and denominator: the nominator describes the group of patients for which the indicator is positive; the denominator describes the group of patients being evaluated. The quotient between both is the indicator score that can be used to evaluate the quality of care (18). An example of a quality indicator with nominator and denominator is given in table 2.

Table 2: Example of a quality indicator with nominator and denominator from Earle et al. (19)

Nominator	Number of cancer patients receiving chemotherapy in the last 14 days of life	50
Denominator	Total number of cancer patients receiving chemotherapy	200
	Indicator score	25%

Properties of quality indicators

To register the information needed to calculate the nominator and denominator of the indicator, validated measurement instruments and/or relevant outcome measures are preferably used (20). Therefore it is important that specific properties delineating the measurement process of the indicator (including nominator and denominator) have to be described before the indicator can be used as a quality indicator (13;21). For an overview of the most common properties, see table 3.

Table 3: Properties of quality indicators

Property	Description
Title of the indicator	What the indicator is about
Reason of the indicator	The relation of the indicator to the quality of care.
Nominator	Population of patients for whom the indicator is positive
Denominator	Population of patient that is evaluated
Exclusion (optional)	The population that needs to be excluded because of irrelevance.
Type of indicator	Structure, process or outcome indicator.
Registration method	Which instrument and which population
Threshold value (optional)	A standard or benchmark

Quality indicators versus outcome measures

Confusion persists about the difference between 'quality indicators' and 'outcome measures', with these concepts often used interchangeably and mistakenly. Outcome measures are an essential component of quality, providing a way to evaluate patient- or family level status and responses to treatment, measured on an individual level (22). An outcome measure evaluates "the change in a patient's current and future health status that can be attributed to preceding healthcare". It expresses quality at an individual level. Quality indicators express quality at an aggregated level, usually the level of a health care service, or an institution, a region or a full country. Although outcome measures are often (and ideally) the basis of quality indicators, in themselves they do not yet have the necessary properties and collection and calculation specifications to serve as quality indicator (23).

The difference between an outcome measure and a quality indicator can perhaps best be illustrated using the example of the place of death (assuming that it would be chosen as an indicator of quality in palliative care). Dying at home can be used as an outcome measure in an individual patient to measure quality of care. However at an individual level it can doubtfully be concluded that quality of care was insufficient if a patient was not able to die at home (e.g. the patient could have died in the hospital because he or she wanted to or because the family wasn't able any more to care for the patient at home). However, when measured at an aggregated level such as the level of a palliative home care service and a nominator (number of patients dying at home) and denominator (number of patients for whom place of death was reported) are described it can perhaps more validly be used as an indicator of quality, particularly if another similar palliative home care service has a substantially higher percentage of home deaths and for no obvious good reason (e.g. structural or patient characteristics).

Summarized we can state that outcome measures can be used to evaluate the care of an individual patient and that quality indicators can be used to overlook the quality of care on aggregated level. Still outcome measures, together with other evaluation tools, need to be at the basis of a good quality indicator and hence are indispensable in quality measurement.

Purpose of quality indicators

Quality indicators can be used for several purposes.
First of all they can provide different information to several stakeholders:

- To patients and families: care services can choose to make quality results public in order to enhance transparency of the care (24-29)
- To caregivers: quality indicators can provide information on the aspects of care that are going well and those who need improvement (24;30)
- To administrators and policy makers: quality indicator scores can show how care providers are performing and which structural support is lacking for the desired outcome (14;24;30)
- To researchers: national and international database of quality results can be used by researchers to compare the quality of care over time and between care services or regions

Second quality indicators can be applied in trials and improvement programs to measure the effect of implemented innovations and quality measurement initiatives (31).

Classifications of quality indicators

Several classifications of quality indicators exist. First, a difference is made between performance and clinical indicators (32). Performance indicators are suitable for external reporting of the quality of care. This means that the quality indicator results are used beyond service level to benchmark and compare quality between different care services. On the other hand clinical indicators are meant for internal quality improvement. This means that a care service uses the quality results within the service in order to identify care aspects that need improvement.

The most wide spread classification of quality indicators is the one by Avedis Donabedian (33). He stated that there are three levels within health care that can classify quality indicators: structure, process and outcome of care. A description of each category with an example of a quality indicator is given in table 4.

Table 4: Structure, process and outcome of care: three types of quality indicators (33)

	Description	Example of quality indicator
Structure of care	Structure denotes the attributes of care services, i.e. material resources (e.g. facilities, equipment), human resources and organizational structure (e.g. medical staff organization)	Nominator: Number of services with clinical guidelines that are revised every 2nd year (34) Denominator: total number of services for which the indicator was measured
Process of care	Process denotes what is actually done in giving and receiving care, i.e. patient's activities in seeking care as well as caregiver's activity in making a diagnosis, recommending or implementing treatment	Nominator: Number of patients assessed by a doctor within 24 hours of referral (34) Denominator: total number of patients referred to the service
Outcome of care	Outcome denotes the effects of care on the health status and quality of life of patients and their family	Nominator: Number of patients with a measurement of the health status (34) Denominator: total number of patients for whom the indicator was measured

In the literature there is some disagreement about which indicator types are most suitable to measure the quality of health care. Until recently, most authors focused on process indicators (34;35). Process indicators, as well as structure indicators, are often inexpensive and easy to measure because they can be reported based on medical charts or administrative databases (36;37). However, such databases can be limited in providing the right information for a good quality assessment (38-40), especially in documenting issues related to communication, outcomes for patient and families and preferences. Precise information on these subjects can only be obtained from patients themselves or their family by measuring outcome indicators (41). Reported information on structure, processes and outcomes of care do not compete with each other, but merely can complement each other. When taking all types of quality indicators into account, the outcomes of care can be improved in two ways. First by adapting structures of care, the outcomes can be indirectly influenced, via accompanying improved processes of care (42). Second it is possible to change the processes themselves to influence the outcomes in a positive way (24). Nevertheless structure, process and outcome of care are interrelated and can influence each other in a positive or negative way. Therefore to measure and improve the quality of care all three kinds of quality indicators have to be taken into account for the best result (43).

Development methodology

Quality indicators should be developed in a careful and transparent manner (32). In this way the developers can assure that they used scientific rigorous methods, and others know in detail the methods used to apply these methods themselves. Until now, several types of methods have been used for developing quality indicators (13). They particularly vary in the extent to which evidence-base is used:

1. *Non-systematic methods*: these methods do not make use of scientific evidence to build the indicators. Also low scientific evidence, such as case studies, might be used.
2. *Systematic methods based on scientific evidence*: the better the evidence for an indicator, the more useful the application of the indicator will be for quality improvement;
3. *Systematic methods based on scientific evidence combined with consensus of experts*: consensus techniques complete the scientific evidence within those areas in health care where the scientific evidence is incomplete, non-existing or too weak. This also increases the face validity of the indicators as important stakeholders are involved in the consensus procedures.
4. *Systematic methods based on guidelines*: the indicators are based on existing guidelines

When developing quality indicators, evidence-base is crucial to make them reliable and valid. In many clinical areas there are few randomized trials to deliver evidence for quality indicators (42). Therefore most authors have stated that ideally, for the development and selection of quality indicators, adequate research evidence should be supplemented by expert consultations, referring to the third group of methods (13;32;34). Within this group, the RAND/UCLA appropriateness method is one of the most robust and valid methods for quality indicator development. It consists of five steps (44):

1. A *systematic literature review* to identify a preliminary set of quality indicators for the area of interest
2. *Recruitment of experts* reflecting the variety of stakeholders in the area of interest
3. A first round *homework assignment* in which the experts score the preliminary set of indicators for 'appropriateness' on a scale from 1 (not appropriate) to 9 (very appropriate)
4. A second round of scoring in a *face-to-face panel meeting*. Only indicators with a median score of 4, 5, 6 or higher but not reaching consensus need to be discussed, modified

where necessary and rescored. The indicators with a median score of 7, 8 or 9 are automatically added to the quality indicator set.

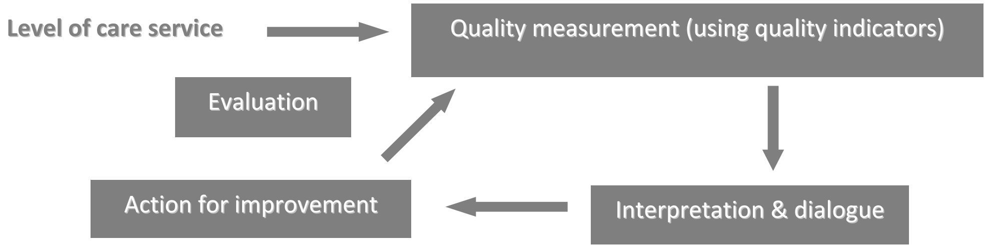
5. Using the second round scores to *decide on the quality indicator set*

Still when applying this type of consensus method, one must always be aware of unexpected influences on the indicator selection of the composition of the panel, the inclusion of grey literature and the panel members' experience with the scoring process. The application of the RAND/UCLA method to develop quality indicators for palliative care in Flanders is described in detail in Chapter 3 of this PhD book.

Use of quality indicators in practice

When using quality indicators within the continuous process of quality monitoring and improvement, it is crucial to know that quality indicators are not meant as an arbitrary quality demarcation but rather give an indication of the quality of care delivered (21). Many factors such as structural components and patients characteristics can have an influence on the quality indicator scores. Therefore when interpreting these scores, one needs to be careful in pronouncing what is good or bad. Standards and benchmarks, necessary for the comparison of quality over time and between different services, can only be set after using an indicator repeatedly and at a reasonably large scale (30). However, irrespective of whether benchmarks are already in place, quality indicators can at all times be used for internal monitoring and improvement by any kind of care service as long as they are embedded in a larger circle of 'measuring – interpreting - improving – evaluating' (Figure 1) (45;46).

Figure 1 Quality indicators embedded in the circle of measuring, interpreting, improving and evaluating



Quality indicators for palliative care

Definition and concept of palliative care

The WHO defines palliative care as (47):

> "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".

The WHO further defines palliative care by stating that it "provides relief from pain and other distressing symptoms affirms life and regards dying as a normal process. It intends neither to hasten nor postpone death. Palliative care integrates the psychological and spiritual aspects of patient care. It offers a support system to help patients live as actively as possible until death and to help the family cope during the patients illness and in their own bereavement. Furthermore, palliative care uses a team approach to address the needs of patients and their families, including bereavement counselling, if indicated. It will enhance quality of life, and may also positively influence the course of illness. It is applicable early in the course of illness, in conjunction with other therapies that are intended to prolong life, such as chemotherapy or radiation therapy, and includes those investigations needed to better understand and manage distressing clinical complications" (48).

In this definition, palliative care does not only focus on patients - like most other disciplines in health care - but also tends to support their family. It goes beyond the dying of the patient as it is meant to help family in their bereavement. Also palliative care tends to influence all important aspects of care and life: physical symptoms but also psychosocial and spiritual burden (49;50). Next to assessment and treatment, also information, communication and tackling the practical burdens of illness are deemed important (51-55). Therefore palliative care differs from other disciplines in health care as it provides holistic care for patients and families (56). This means that when defining 'quality palliative care', this multifaceted character needs to be taken into account (54;57).

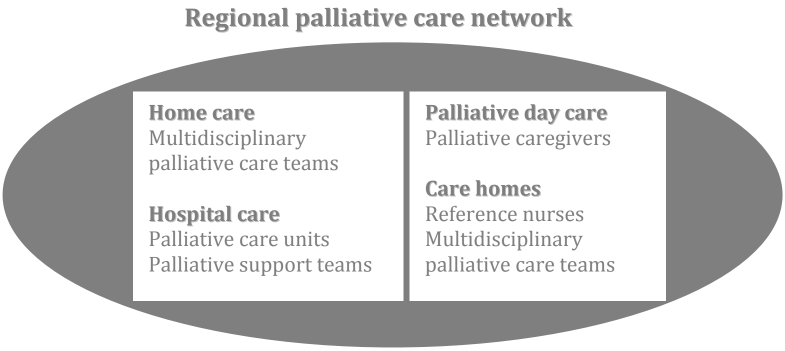
Also important to note is that palliative care can be delivered in regular health care as well as by specialized palliative care services that support the regular caregivers (58;59). In most countries palliative care is therefore organized in a different way, coherent to the existing health care system.

Organization of palliative care in Flanders, Belgium

In Belgium, the Government has issued a law on palliative care in 2002, to optimize the organization, structure and financing of palliative care (60). The law states that every patient nearing the end of life has the equal right to receive palliative care and to be fully informed about his health condition and the options within palliative care. The goal was to embed palliative care into general health care rather than making it a specialist discipline (61). Furthermore the law prescribed that a federal evaluation unit should be assembled, in order to identify remaining needs in the field of palliative care.

To ensure good coordination of palliative care across all types of care settings, Belgium was divided into regional palliative care networks. These networks are responsible for public dissemination, organization of training for caregivers and cooperation between the different palliative care services (62-65). Every palliative care network needs to have a multidisciplinary palliative home care team at its disposal. Next to this team there are 4 other specialized palliative care services available: palliative care units and multidisciplinary mobile palliative support teams in hospital care and palliative reference nurses in residential long-term care (figure 2). All specialized services cooperate with primary and secondary caregivers and have a multidisciplinary composition. At the moment of publication of this thesis in Flanders there are 15 regional palliative care networks with each 1 multidisciplinary palliative home care team, 29 palliative care units in hospitals with 209 inpatient palliative care beds (6 to 12 beds per unit), 78 multidisciplinary mobile palliative support teams in 96 hospitals, 460 out of 980 care homes with a palliative reference nurse and 5 palliative day care centers. The working of each separate specialized palliative care service is described:

Figure 2 Different types of specialized palliative care within the regional networks in Flanders



Multidisciplinary palliative home care teams support family physicians and community nurses in providing palliative care to patients at home. This is done by informing them on palliative care and by providing them psychological and moral support. In principle, they do not take over the care from the primary caregivers although they in practice provide several aspects of care that require more specialized palliative care skills (including more complicated pain and symptom alleviation). They need to have an educating effect on primary caregivers (63-66).

Multidisciplinary mobile palliative support teams in hospitals are at the disposal of the different wards of a hospital with patients with particular palliative care needs, to the patients themselves and their families. They also perform a training and dissemination function amongst their colleges in the hospital (63;64;67;68).

Palliative care units are separate wards in a hospital comprising 6 to 12 beds for palliative care purposes. They are designed to care for patients and families with more complex physical, psychological and/or spiritual needs that cannot be met in the home or care home setting, either on temporary basis or until the patient dies (63-65;69).

Palliative care reference nurses in residential long-term care are at the disposal of the caregivers who provide care to the care home residents with palliative needs. They are responsible for sensitization, advising and providing information to their colleges (64;65;70;71).

Palliative (or supportive) day care centers provide ambulatory palliative support to homecare, to give the main caregiver the opportunity to take some spare time so patients can be kept at home for a longer period. One or more days a week, patients can meet other patients, talk to staff and become involved in activities (63-65).

A need for quality indicators in palliative care

Palliative care, unlike other health care services, provides holistic care and therefore covers many aspects of care at the same time (e.g. combination of physical, social, psychological and spiritual elements of the care, communication, the bereavement support for family) (49-55) . It focuses on the quality of life of patients as well as of their families (47). When aiming at monitoring the quality of palliative care it is simply not sufficient to implement the common indicators of general health care (49;72). Moreover it is even not possible to select some ‘core indicators’ for palliative care (73). In order to be able to address its multidimensional and multidisciplinary approach, a quality indicator set for palliative care should contain (51;52;54;57;74-79):

- All domains covered by palliative care
- The perspectives of all stakeholders
- Structure, process as well as outcome of care

At the start of this thesis in 2009, few initiatives were described in the literature trying to measure the quality of palliative care. Some of the few countries already initiating systematic monitoring of quality within palliative care were The Netherlands, Australia and The United States of America, giving the example for other research teams and policy makers (19;30;80;81). In the meanwhile some more quality assessment initiatives have been described in the literature indicating great interest and desire for objective quality measurement in this field (23;82-91). Still, many problems occur concerning the comprehensiveness of the existing quality indicator sets (92). First, most of the initiatives do not strictly make use of quality indicators but rather of outcome measures (23;81;82;84). To be able to capture the quality of care on an aggregated level, well defined quality indicators are necessary. A second problem that often occurs is that the quality indicator sets are developed for specific patient populations such as cancer patients or vulnerable elderly (87;89-91).

It is a fact that the palliative population is rather difficult to identify (12). Despite this, it is important that quality indicator sets for palliative care focus on all patient groups in order to be able to involve the whole field in the quality measurement. Third, some quality indicator sets rely on specific data sources such as administrative databases or medical charts (19;86;88). As these either only record reimbursed or billed care provision or poorly report information about the care, they are not always comprehensive or reliable. Fourth, some indicator sets contain only one type of quality indicators to measure the quality of care, such as outcome indicators (30). This might be problematic because sustainable quality improvement is best reached based on information on structure, process as well as outcome of care to capture the whole dynamics of care.

To conclude, no indicator set for palliative care has been developed yet that covers all important domains, the perspectives of all stakeholders and structure, process as well as outcome of care. Therefore this thesis describes the first initiative to develop such a comprehensive set of quality indicators for specialized palliative care in Flanders (93), taking into account all important domains, the perspectives of all stakeholders and structure, process as well as outcome of care. To guarantee the wide use of quality indicators to systematic monitor and improve the quality of care, it is important to combine a scientific rigorous development method, a feasibility study to test the indicators' validity and usefulness, and a preparation phase for implementation by identifying barriers and facilitators for implementation of the quality indicators (21;94).

Developing a set of quality indicators for specialized palliative care

Before quality of palliative care can systematically be measured and improved, a valid and reliable set of quality indicators needs to be developed (13;14). From the literature we can conclude that all conditions, definitions, attributes and methods that apply to quality indicators on general health care services also apply to those on palliative care.

When developing a quality indicator set for palliative care, two key questions need to be beard in mind (13):

- Which quality indicators already exist for palliative care?
- Which domains and stakeholders perspectives need to be included in order to measure overall quality of palliative care?

Part II of this thesis extensively describes the rigorous development method we used. We tried to answer the key questions as follows:

- Identify existing indicators by using of a systematic literature review (Chapter 2)
- Identify domains, stakeholder perspectives and accompanying indicators of quality palliative care by using a literature review and expert consultations (Chapter 3)

Indicator validation in palliative care practice

Before quality indicators can be used at a widespread national level, they have to be tested for key attributes such as validity and potential for improvement (13;95;96). Furthermore they have to be found clinically relevant and manageable for the caregivers that will have to use them (30). As part of the development process, quality indicators hence have to be validated by taking into account criteria such as feasibility, usefulness, face validity, content validity, discriminative ability and missing data (95). So far, only two quality indicator sets for palliative care were extensively tested and validated during the development process (30;89).

The feasibility study of the comprehensive set of quality indicators for palliative care was conducted within 9 palliative care services in Flanders. Methods and results of this study are described in Chapter 4 of Part III. As a result of the feasibility study to fine-tune the indicator set, chapter 5 describes the selection of a minimal indicator set.

Identification of barriers and facilitators for the systematic use of quality indicators in palliative care practice

Before the quality indicators can be proposed for general use in palliative care services we need to investigate and understand how quality indicators can be optimally implemented in practice (91;92). Therefore, after having developed and tested a quality indicator set, conditions for further and wider use have to be studied in order to develop successful implementation strategies (45;96-98).

In Part IV of this thesis we firstly describe how the indicator set for palliative care was prepared for wide implementation in palliative care services in Flanders by developing a successful implementation strategy using facilitator and barrier identification (chapter 6). Secondly we describe how palliative care services can use the quality indicator set to measure and evaluate the quality of their care in order to improve it (chapter 7).

Research aims and structure of the PhD thesis

Research aims

The overall goal of this thesis was *to develop a comprehensive and implementable indicator set for palliative care services in Flanders*.

To achieve this, a **3 step development trajectory** was followed: 1) developing the indicator set, 2) testing the feasibility of the indicator set in practice and 3) preparing the implementation of the indicator set.

Step 1: Developing quality indicators for palliative care services in Flanders

The research objectives are:

1. What international quality indicators already exist to measure the quality of palliative care? (Chapter 2)
2. What method should be used to develop quality indicators that are suitable for measuring the quality of palliative care? (chapter 3)

Step 2: Testing and fine-tuning the developed quality indicator set

The research objectives are:

3. Are the quality indicators selected for palliative care in Flanders and accompanying measurement procedure feasible, usable and valid? (Chapter 4)
4. What quality indicators need to be selected for a minimal set in order to measure quality of care in the quickest and most efficient but still comprehensive manner? (Chapter 5)

Step 3: Towards an implementable quality indicator set for palliative care services in Flanders

5. What are possible barriers and facilitators, from professional caregivers' perspective, when implementing quality indicators into the palliative care services in Flanders? (Chapter 6)
6. How can palliative care services monitor the quality of their care using quality indicators? (Chapter 7)

Structure of the PhD thesis

Part II of this thesis describes the first step, i.e. developing a quality indicator set for palliative care services in Flanders. In chapter 2 the update of an extensive literature review is presented (addressing research question 1). The rigorous development process is described in chapter 3 (addressing research questions 2).

Part III of this thesis describes the second step, i.e. the testing and fine-tuning of the developed quality indicators. Chapter 4 describes the feasibility study of the quality indicator set in palliative practice (addressing research question 3). In chapter 5 the methods of a RAND/UCLA expert panel is described to select a minimal set for palliative care in Flanders (addressing research question 4).

Part IV of this thesis describes the third step, i.e. preparing the implementation of the quality indicators in palliative care services in Flanders. Chapter 6 describes the process of focus group interviews for identification of barriers and facilitators in the use of quality indicators within palliative care services in Flanders (addressing research question 5). Chapter 7 gives an overview of how palliative care services can use the quality indicators for systematic monitoring and hence improvement of their care (chapter 7).

Finally chapter 8 in part V presents a general discussion on the major findings in this thesis with recommendations for future research as well as future policy strategies for palliative care.

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PART II

Developing quality indicators for palliative care services in Flanders

Chapter 2

Quality Indicators for Palliative Care: update of a systematic review

Maaike L. De Roo, Kathleen Leemans, Susanne J.J. Claessen, Joachim Cohen,
H. Roeline W. Pasman, Luc Deliens, Anneke L. Francke, on behalf of EURO IMPACT

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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 was 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 National Consensus Program. 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, 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 giving 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 today's palliative care, 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 besides developing these guidelines had to be the development, testing and implementation of quality indicators, in order 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 started 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 paper 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 are 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 on condition that 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*., 2010 (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 (KL and JC or SC and MDR) 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 (AF) 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 (KL and MDR or SC and MDR) independently. Discrepancies between reviewers were discussed and in those cases where a consensus could not be reached, one of the other co-authors (AF) 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 (KL and MDR or SC and MDR) into the domains of palliative care defined by the National Consensus Program (4;6;7).

These domains are:

(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, and developing and implementing comprehensive social care plans).

(5) *‘Spiritual, Religious, and Existential Aspects of Care’* (e.g. providing information about availability of spiritual care services to patient or family).

(6) *‘Cultural Aspects of Care’* (e.g. incorporating cultural assessments such as 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, and 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, and 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 (KL and MDR or SC and MDR) for 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 should therefore 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 [4] by the number of items in that category [3, 3 or 9] and the number of evaluators [2]. The minimum possible score was calculated at the same time by using the minimum score per item [1].

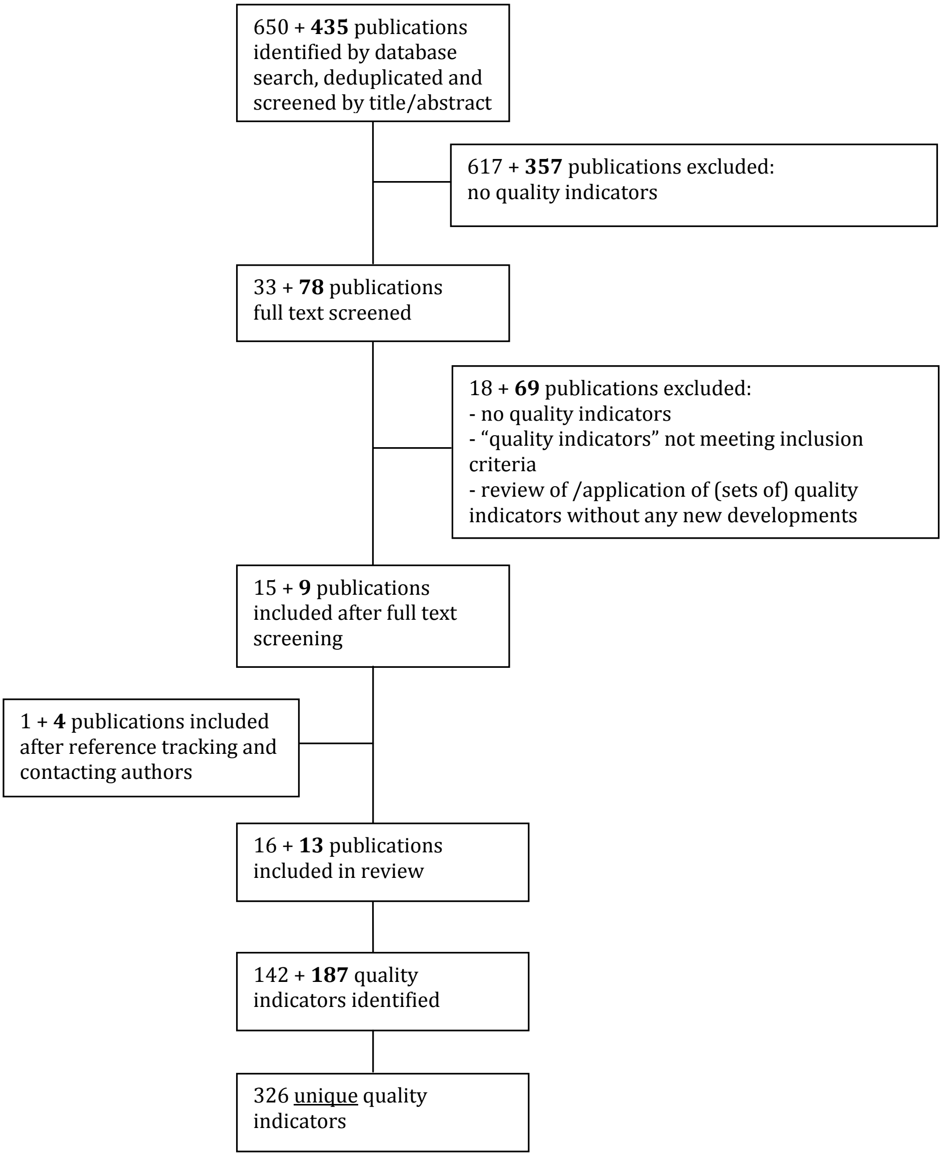
The standardized category score is the total score per category, minus the minimum possible score for that category, divided by the maximum possible score minus the minimum possible score times 100%. This standardized score ranges between 0% and 100%, with a higher score indicating a higher methodological 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 this update in 2011. 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 (see 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 Box 1].

Box 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 (not published in this thesis).

Table 1: Characteristics of the quality indicator sets

Author(s), year country, references	**Population**	**Setting**	**Number of indicators: total and per type**	**Number of indicators per domain**	**Example of indicator (type/domain)**
Earle et al., 2006 USA (32;33;50)	Patients with cancer	Not specified	Total: 7 Outcome: 0 Process: 7 Structure: 0	domain 1: 3 domain 2: 0 domain 3: 0 domain 4: 0 domain 5: 0 domain 6: 0 domain 7: 4 domain 8: 0	‘Proportion with more than one hospitalization in the last 30 days of life’ Numerator: Patients who died from cancer and had > 1 hospitalization in the last 30 days of life Denominator: Patients who died from cancer Performance standard: < 4% (process/domain 7)
NEW Grunfeld et al., 2008 USA (18;34)	Cancer patients in their last 6 months of life	All settings where end-of-life care is provided	Total: 10 Outcome: 4 Process: 6 Structure: 0	domain 1: 4 domain 2: 2 domain 3: 0 domain 4: 0 domain 5: 0 domain 6: 0 domain 7: 4 domain 8: 0	‘Enrollment in palliative care within 3 days of death’ Numerator: No. of cases enrolled in palliative care within three days prior to death Denominator: All cases enrolled in palliative care (process/domain 7)
Yabroff et al., 2004 USA 49)	Patients with cancer (as prototype)	Not specified	Total: 10 Outcome: 5 Process: 5 Structure: 0	domain 1: 8 domain 2: 1 domain 3: 1 domain 4: 0 domain 5: 0 domain 6: 0 domain 7: 0 domain 8: 0	‘Percentage of patients and family/caregivers within health facilities or systems that understand and are satisfied with provider communication about prognosis’ No further specifications (outcome/domain 1)
NEW Lorenz et al., 2009 USA (22;23)	Adults with cancer	Major clinical settings where cancer patients seek care, including general practice and oncology settings	Total: 41 Outcome: 0 Process: 41 Structure: 0	domain 1: 2 domain 2: 33 domain 3: 3 domain 4: 0 domain 5: 0 domain 6: 0 domain 7: 0 domain 8: 3	‘IF a cancer patient is admitted to a hospital THEN there should be screening for the presence or absence of pain’ No further specifications (process/domain 2)

Table 1: Characteristics of the quality indicator sets – continued

NEW Miyashita et al., 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 Outcome: 19 Process: 18 Structure: 0	domain 1: 6 domain 2: 8 domain 3: 4 domain 4: 5 domain 5: 2 domain 6: 1 domain 7: 1 domain 8: 10	'Symptom control: Physician's prescription order for dyspnea' <u>Numerator</u>: Number of patients for whom this indicator was documented on admission or within the last 2 weeks of the hospitalization <u>Denominator</u>: All patients who died (retrospectively identified) (process/domain 2)
Peruselli et al., 1997 Italy (41)	Terminal patients	Home care	Total: 54 Outcome: 43 Process: 11 Structure: 0	domain 1: 17 domain 2: 18 domain 3: 14 domain 4: 3 domain 5: 0 domain 6: 0 domain 7: 2 domain 8: 0	'Palliative care services must meet the physical, psychological, social and spiritual needs of patients' <u>Numerator</u>: 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) <u>Denominator</u>: Total patients x 100 <u>Performance standard</u>: 75% (outcome/domain 2)
Keay et al., 1994 USA (35)	Terminally ill in nursing homes	Nursing home	Total: 7 Outcome: 1‡ Process: 7 Structure: 0	domain 1: 0 domain 2: 3 domain 3: 1 domain 4: 0 domain 5: 0 domain 6: 0 domain 7: 1 domain 8: 2	'If terminally ill patient is reported to be in pain, this is addressed by the physician and active attempts are made to reduce pain' <u>Exclusion</u>: Minor pain symptoms in cognitively intact patients <u>Performance standard</u>: 100% (process + outcome/domain 2)
Lorenz et al., 2007 USA (30;36;38;42;47)	Vulnerable elderly	Not specified *	Total: 23 Outcome: 0 Process: 23 Structure: 0	domain 1: 2 domain 2: 8 domain 3: 1 domain 4: 1 domain 5: 0 domain 6: 0 domain 7: 1 domain 8: 10	'IF a 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' <u>No further specifications</u> (process/domain 8)

Table 1: Characteristics of the quality indicator sets – continued

^{NEW} van der Ploeg et al., 2008 The Netherlands (21)	Vulnerable elders Adapted and shortened version of ACOVE's end-of-life care subset	Care for vulnerable elders in general, this publication is currently focusing on care provided by the general practitioner	Total: $6^{\#}$ Outcome: 2 Process: 4 Structure: 0	domain 1: 0 domain 2: 4 domain 3: 2 domain 4: 1 domain 5: 0 domain 6: 0 domain 7: 1 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: • Pain; • Anxiety, depression; • Vomiting and dyspnea; • Spiritual and existential concerns; • Caregiver burdens/need for practical assistance; • Wishes concerning medical treatment and care at the end of life; a discussion about and if possible the determination of a surrogate decision maker' No further specifications (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 Outcome: 4 Process: 4 Structure: 0	domain 1: 1 domain 2: 3 domain 3: 2 domain 4: 0 domain 5: 0 domain 6: 0 domain 7: 2 domain 8: 0	'Family evaluation of hospice care: Symptom management Questions (to family): While under the care of hospice, did the patient have any feelings of anxiety or sadness? How much help in dealing with these feelings did the patient receive?' Numerator: Those who received too much or too little help concerning anxiety/sadness Denominator: Those who experience anxiety/sadness Exclusion: Patients who are not enrolled in a hospice program or have disenrolled from a hospice program. Live discharged are excluded (outcome/domain 3)
^{NEW} Schenck et al., 2010 USA (25)	Patients in hospice or palliative care	Hospice or palliative care	Total: 28 Outcome: 10‡ Process: 19 Structure: 0	domain 1: 2 domain 2: 17 domain 3: 3 domain 4: 0 domain 5: 1 domain 6: 0 domain 7: 0 domain 8: 5	'For patients who screened positive for pain, the percent with any treatment within 1 day of screening' Numerator: Number of patients with (0<=Pain Treatment Time<=1) and (pain treatment="Y") [Pain Treatment Time = date of treatment – pain assessment date] Denominator: Patients with pain (process/domain 2)

Table 1: Characteristics of the quality indicator sets – continued

Nelson et al., 2006 Mularski et al., 2006 USA (39;40)†	Critically ill	Intensive care units (ICU)	Total: 21† Outcome: 2‡ Process: 15 Structure: 5	domain 1: 9 domain 2: 5 domain 3: 0 domain 4: 2 domain 5: 1 domain 6: 0 domain 7: 1 domain 8: 4	'Documentation of offering of psychosocial support within the first 72 hours of admission to the ICU' Numerator: Total number of patients in the ICU for > 72 hours with psychosocial support offered to the patient or family by any team member Denominator: Total number of patients in the ICU for > 72 hours Exclusion: Comatose patients (eg Glasgow Coma Score of 2T or 3) with no family member or friend identified (process/domain 4)
Twaddle et al., 2007 USA (46)	Patients in hospitals	Hospital	Total: 11 Outcome: 2 Process: 9 Structure: 0	domain 1: 4 domain 2: 6 domain 3: 1 domain 4: 0 domain 5: 0 domain 6: 0 domain 7: 0 domain 8: 0	'Percentage of all patients with documentation of dyspnea assessment within 48 hours of admission' Performance standard: 90% (process/domain 2)
NEW Claessen et al., 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 Outcome: 10 Process: 1 Structure: 0	domain 1: 1 domain 2: 4 domain 3: 2 domain 4: 0 domain 5: 2 domain 6: 0 domain 7: 1 domain 8: 1	'Care for psychosocial well-being of patients: Percentage of patients who feel depressed' Numerator: The number of patients with a feeling depressed score of 4 or above on the NRS (average over 3 days) Denominator: The total number of patients for whom this indicator is measured Exclusion: Patients with moderate to (very) severe cognitive impairments, young children, psychiatric and/or confused patients, and comatose and deeply sedated patients (outcome/domain 3)

Table 1: Characteristics of the quality indicator sets – continued

^{NEW} Eagar et al., 2010 Australia (24;28)	Not specified	Specialist palliative care settings	Total: 3 Outcome: 2 Process: 0 Structure: 1	domain 1: 2 domain 2: 1 domain 3: 0 domain 4: 0 domain 5: 0 domain 6: 0 domain 7: 0 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’ <u>No further specifications</u> (structure/domain 1)
^{NEW} Quality Markers, 2009 United Kingdom (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 Outcome: 9 Process: 11 Structure: 14	domain 1: 23 domain 2: 0 domain 3: 0 domain 4: 2 domain 5: 0 domain 6: 0 domain 7: 5 domain 8: 4	‘Proportion of individuals whose preferred place for care has been recorded’ <u>No further specifications</u> (outcome/domain 8)

Table 1: Characteristics of the quality indicator sets – continued

NEW End of Life Care Quality Assessment, 2011 United Kingdom (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^ Outcome: 4~ Process: 13 Structure: 3	domain 1: 11 domain 2: 0 domain 3: 0 domain 4: 1 domain 5: 0 domain 6: 0 domain 7: 3 domain 8: 4	‘Individuals have an agreed care plan’ Numerator: Number of deceased patients with care plan in place. Denominator: Total deaths for same catchment and time period Performance standard: Care plans in place for all patients approaching the end of life (process/domain 8)

NEW These quality indicator sets have been found in this update.

* Saliba et al. (42) tested the feasibility of a selection of the quality indicators for nursing home residents.

† 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. The total number of quality indicators in this set is the total of both sets.

‡ One indicator contained outcome and process of care.

\# One indicator suits 4 NCP-categories.

^ Two indicators suit 2 NCP-categories.

~ Two indicators contained outcome and process of care.

$ Not all indicators do apply to all settings.

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); afterwards it 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 sets were found 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).

Quality indicators per domain of palliative care

All 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 [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, e.g. 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, 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 [Table 2]. (e.g. van der Ploeg 2008, see Table 1). Also a substantial number of outcome indicators were 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

	Type of indicator			
Domains	**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.

$ Three indicators contained outcome and process of care.

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

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 [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)**

	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
NEW Palliative cancer care (Grunfeld et al.) (18;34)	83	78	39
Palliative cancer care (Yabroff et al.) (49)	22	56	17
NEW Palliative cancer care (Lorenz et al.) (22;23)	61	89	57
NEW Palliative cancer care (Miyashita et al.) (19;20)	56	28	31
Family evaluation of hospice care (NHPCO) (44;45;50) ‡	78	72	46
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
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
NEW All settings for palliative care in the Netherlands (Claessen et al.) (17;29)	89	89	43
NEW Specialist palliative care (Eagar et al.) (24;28)	22	11	48
NEW Several settings for palliative care in the UK (Quality Markers) (26)	44	11	11
NEW Several settings for palliative care in the UK (End of Life Care Quality Assessment) (27)	50	33	22

* Appraisal of Indicators through Research and Evaluation (AIRE) 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. While 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 US.

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. On the other hand, 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 consisted of 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 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 cheap 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, i.e. referring to all types of patients and institutions; hence all three types of indicators should be taken into account. In some cases, e.g. 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 (2;4;53;55-57) that a combination of structure, process, and outcome indicators may be most appropriate to measure the quality of palliative care.

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 past four years 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 in the United States; 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 noticeable 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 Earle *et al*. set (6;32;33) and the Schenk *et al*. set (25) had the highest methodological scores following the AIRE instrument. The developmental process for 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 a low score 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 grey 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 might 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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Chapter 3

Towards a standardized method of developing quality indicators for palliative care: protocol of the Quality indicators for Palliative Care (Q-PAC) study.

Kathleen Leemans, Joachim Cohen, Anneke L. Francke, Robert Vander Stichele,
Susanne J.J. Claessen, Lieve Van den Block, Luc Deliens

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Abstract

Background: In recent years, there have been several studies, using a wide variety of methods, aimed at developing quality indicators for palliative care. In this Quality Indicators for Palliative Care study (Q-PAC study) we have applied a scientifically rigorous method to develop a comprehensive and valid quality indicator set which can contribute to a standardized method for use in other countries.

Methods and design: Firstly, an extensive literature review identified existing international quality indicators and relevant themes for measuring quality in palliative care. Secondly, the most relevant of these were selected by an expert panel. Thirdly, those prioritized by the experts were scored by a second multidisciplinary expert panel for usability and relevance, in keeping with the RAND/UCLA-method, combining evidence with consensus among stakeholders. This panel included carers and policymakers as well as patients and next-of-kin. Fourthly, the draft set was tested and evaluated in practice for usability and feasibility; the indicators were then translated into questionnaires presented to patients, next-of-kin and care providers. To encourage the acceptance and use of the indicators, stakeholders, including national palliative care organizations, were involved throughout the whole project.

Conclusion: Our indicator development trajectory resulted in a set of quality indicators applicable to all patients in all palliative care settings. The set includes patient and relative perspectives and includes outcome, process and structure indicators. Our method can contribute internationally to a more standardized and rigorous approach to developing quality indicators for palliative care.

Background

Quality of care is of interest to everyone receiving or providing palliative care (1). Evaluation of quality informs care providers, administrators and policymakers about whether patients and their families are receiving care that fits their needs (2-4). The challenge for quality improvement in palliative care is to develop effective ways for the quick and efficient assessment of service performance and outcomes, as this facilitates the modification of services and practices in order to improve the quality of care at individual and institutional levels (5-8). For this purpose, quality indicators specifically for palliative care can be used to address issues unique to this type of care (9).

Although in the past decade a variety of studies have focused on quality indicators for palliative care, the methods found in the literature by which indicators were developed were not always clearly presented and not always seemed to follow a systematic approach involving different steps of the development process (10-26). Two recent systematic efforts have developed a nationwide quality register system to measure outcomes and quality of palliative care services: the Palliative Care Outcomes Collaboration (PCOC)-study in Australia (27), and a similar registration project in Sweden (28). While these projects have resulted in very useful national quality monitoring systems, they do not strictly make use of quality indicators but mainly focus on outcome measures. Additionally they did not seem to aim for a level of comprehensiveness necessary to evaluate the various dimensions of palliative care.

It appears that there is a need for a more standardized method of developing a comprehensive quality indicator set. Even at a more fundamental level, however, there is also a need for a common understanding of what quality indicators are. Quality indicators are well-defined and measurable aspects of care that give an indication of the quality of care delivered; they are generally expressed in a number or percentage, address a specific aspect of care or a related outcome, and are expressed at an aggregated level, often the level of care organisations (29-32). They have to be clinically relevant, manageable and based on existing evidence, or consensus in the absence of such evidence (30). Specific properties have to be described: a numerator (ie for which patients the indicator is positive) and a denominator (the group of patients being evaluated), a threshold value as a performance standard and exclusion criteria. Validated measurement instruments and relevant outcome measures are preferably used (33). Confusion persists about outcome measures, measurement instruments and quality indicators, with these concepts often used interchangeably and mistakenly. Outcome measures are an essential component of quality, providing a way to evaluate patient- or family-level status and responses to treatment, measured on an individual level (34). However, as quality indicators, they do not have standardized specifications detailing the eligible population, data collection procedures and types of analysis needed to calculate them (24) (see Box 1).

Box 1: Definitions and examples of outcome measures, quality indicators and quality measurement instruments

	Outcome measure/ variable	**Quality indicator**	**Quality measurement instrument**
Definition	An essential component of quality whereby the focus lies on patient's or relatives outcomes, measured at an individual level.	Well defined and measurable aspect of care, generally expressed in a number or percentage, addressing a specific aspect of care or a related outcome. Quality indicators are usually expressed on aggregated level.	Instruments that can be used to monitor quality of care.
Characteristics	Concerns outcomes of care	Concerns structure, process or outcomes of care	Concerns structure, process or outcomes of care
	In palliative care, outcome measures provide a way to evaluate patient- and family-level status and response to treatment for symptoms and conditions in physical, psychological and other domains	Clinically relevant, manageable and based on existing evidence, or if not applicable on consensus Contains standardized specifications detailing the eligible population, data collection procedures and types of analyses needed to calculate the indicator	These instruments are used to measure outcome measures on individual level as well as quality indicators on aggregated level
	Individual level	Aggregated level	Individual and aggregated level
Example	Pain intensity	Percentage of patients with moderate to severe pain (10)	Numerated rating scales (NRS)
	Quality of life Comfort	Extent to which patients indicate that caregivers respect their life stance (10)	McGill Quality of Life Questionnaire (44)
	Patient's appraisal of the quality of care Relative's appraisal of the quality of care	Extent to which direct relatives felt supported by the caregivers immediately after the patient's death (10)	VOICES questionnaire (42;43)

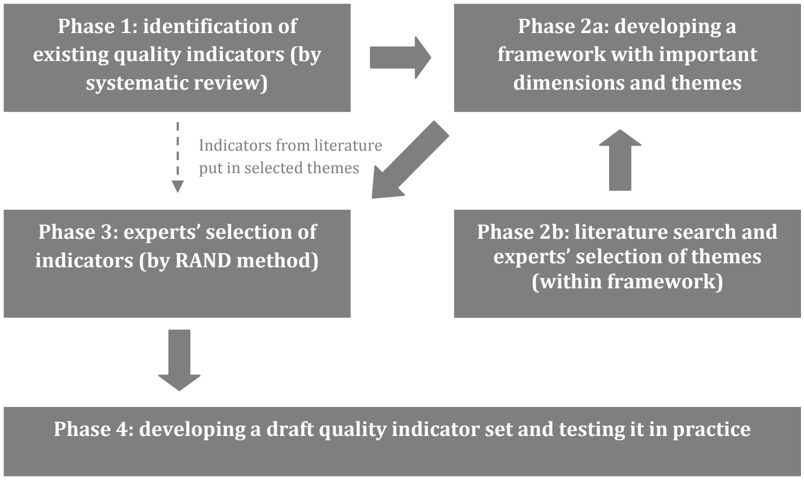
Following the model proposed by Donabedian, quality indicators should be monitored in all three major areas of health care: structure, process and outcome (35). Structure refers to the organization of care (eg presence of a written policy about visiting patients in the ICU), whereas process refers to the interaction between providers and receivers of care (eg psychosocial support being offered within the first 72 hours of admission to the ICU) (36). Outcomes of care are at the level of the beneficiary of that care (eg adequate treatment of pain) (36).

With good examples of systematic and scientifically rigorous development trajectories for quality indicators for palliative care lacking in the literature, we intend this article to contribute to the establishment of a scientifically rigorous standardized and applicable method of measuring usable quality indicators. We do this by describing the protocol of a study developing a quality indicators set for palliative care for adults in Flanders (the Flemish speaking part of Belgium), applicable in all settings providing palliative care, thus providing an example usable by other countries interested in monitoring the quality of palliative care.

Methods and design

In order to develop a comprehensive set of quality indicators to monitor the quality of palliative care in Flanders, four phases were followed in the development process: 1) identification of existing quality indicators, 2) development of a framework for quality of palliative care, 3) indicator selection by expert consultations and 4) testing the draft quality indicator set in palliative practice (figure 1). The protocol of the present study was approved by the Ethical Review Board of Brussels University Hospital of the Vrije Universiteit Brussel.

Figure 1: Flowchart of the 4 phases of the Flanders Study to develop Quality Indicators for Palliative Care



Phase 1: identification of existing quality indicators

To get an overview of previous attempts to develop quality indicators for palliative care, a thorough systematic literature review was performed, building on a review done in 2007 by Pasman et al (36). With the field of quality indicators and the literature on quality measurements in palliative care developing quickly, it was important to update the existing review using the same method and search strategies but including the most recent literature published between December 2007 and May 2009.

As in the original review, we searched four international databases (Pubmed, PsychINFO, EMBASE and CINAHL). Two independent reviewers (KL and JC) followed the same procedures as in the original review by Pasman et al (results of this review update are integrated into a paper published in Journal of Pain and Symptom Management (37)).

Phase 2: identifying domains and themes of quality palliative care

To achieve eventual comprehensiveness in the set of quality indicators we conceived a conceptual framework based on publications focussing on the determination of high quality palliative care consisting of several domains (38-40): 1) physical, 2) psychological, social and existential, 3) information, communication, planning and decision making with patients, 4) with family and 5) with other carers, 6) type of care, 7) coordination and continuity, 8) support of friend or family carers and 9) structure of care (table 1). Within these nine domains, we distinguished several themes (see table 2 for an example of one domain with different themes).

Table 1: Selected domains for the quality of palliative care in Flanders

1.	Physical treatment and care
2.	Psychological, social and existential treatment and care
3.	Information, communication, planning and decision making with the patient
4.	Information, communication, planning and decision making with the family
5.	Information, communication, planning and decision making with other caregivers
6.	Type of care at the end of life
7.	Coordination and continuity of care
8.	Support of family and informal caregivers
9.	Structure of care

Table 2: Example of themes within domains: Domain 1 'Physical treatment and care'

	Process of care
1.	To measure or evaluate general symptom burden
2.	To measure or evaluate pain
3.	To measure or evaluate nausea and problems with digestion
4.	To measure or evaluate fatigue and insomnia
5.	To measure or evaluate decubitus
6.	To measure or evaluate appetite
7.	To measure or evaluate problems with respiration/tightness of the chest
8.	To measure or evaluate delirium
9.	To measure or evaluate complaints on the mouth
10.	To treat or care for physical symptoms once observed with the patient
11.	Mentioning in the patient's file the presence of symptoms
12.	Mentioning in the patient's file the offered treatment and/or medication for the purpose of physical problems
13.	Mentioning in the patient's file the result of the offered treatment and/or medication for the purpose of physical problems
	Outcome of care
1.	Low general symptom burden
2.	Absence of pain
3.	Absence of problems with respiration/ tightness of the chest
4.	Absence of delirium
5.	Absence of decubitus
6.	Absence of fatigue and insomnia
7.	Absence of complaints of the mouth
8.	Absence of nausea and problems with digestion
9.	A good appetite

In order to select the themes most important to quality palliative care we held a consultation of experts representing all relevant actors in palliative care, including patient and family perspectives. The panel consisted of nurses and other caregivers from all different specialized palliative care services, physicians from different specialities, coordinators of the Flemish Palliative Care networks, volunteers, spiritual and religious counsellors, bereaved family members and representatives of palliative patients i.e. large patient organisations such as the Flemish Cancer League and the Flemish Advisory Board for the Elderly.

The panel was asked to score each theme, as identified through the literature, on a scale from 1 (least important) to 5 (most important). Additionally we asked them to select the three most important themes per domain (questionnaires available upon request). Per domain themes were ranked from most important to least important based on the mean scores and the frequency with which the theme was indicated as most important within the domain. Based on the mean scoring (highest tertile across all domains) a number of themes were selected. To be selected, there had to be consensus among the panel members for each indicator, i.e. not more than four members scoring outside the mean range (1-3, 4-6, 7-9). With every domain not then represented, we included one additional theme most often indicated as one of the three most important themes within the domains that were underrepresented. We choose to preserve the nine domains because the research team decided that all domains should be covered in order to have a comprehensive set. Additionally, experts were able to identify additional themes that did not come out of the literature review in a separate box for each domain and these were added if consensus among the experts was reached (i.e. more than one expert added this theme). .

Phase 3: indicator selection by expert consultation

The selected themes were then translated into quality indicators (i.e. with standardized specifications detailing the eligible population, data collection procedures, numerator and denominator), using the quality indicators found in the systematic literature review in the first phase. Then a second consecutive multidisciplinary palliative care expert panel was organized for another selection round. This panel, like the first panel, consisted of researchers in quality measurement or in palliative care, nurses and other caregivers in the field of palliative care, caregivers with a policy task in palliative care, bereaved family members and patient representatives. The experts could add quality indicators important to them not presented in the list and could discard those they found less important. For social and existential aspects of care, no indicators were found in the literature so experts were asked to suggest well-defined and measurable quality indicators for further development.

Unlike with the first expert consultation, we put together the second panel following the appropriateness method of the Research ANd Development corporation in collaboration with the University of California at Los Angeles (RAND/UCLA) (41). This is the only systematic method for selecting quality indicators combining evidence with consensus among stakeholders. We chose to follow this method because, particularly for palliative care, quality indicators have to be developed using other evidence alongside expert opinion (29) as this area of health care has a limited or methodologically weak evidence base. Within this RAND/UCLA-method we executed the five prescribed steps (42):

1. Comprehensive literature review on the topic (i.e. systematic literature review in phase 1) and recommendation of a preliminary set of quality indicators within the quality framework obtained through the first expert panel
2. Recruiting expert clinicians from professional organisations reflecting the variety of specialities in palliative care and inviting them to join a panel for a two-stage process to rate the validity of the indicators. These experts included a representative from a patient organisation and a next-of-kin (eg partner, relative or friend most closely involved), as in the first panel round
3. Sending the draft indicators by post to the panel members, who rated the indicators in terms of appropriateness and relevance as measures of quality on a scale from 1 (not appropriate or not necessary) to 9 (very appropriate or very necessary) (questionnaires available upon request)
4. Feeding back first-round scores to the panellists for a second round of scoring in a face-to-face panel meeting. Only indicators with a median score of 4, 5, 6 or higher but not reaching consensus were discussed, modified where necessary and rescored. The indicators with a median score of 7, 8 or 9 were automatically added to the quality indicator set and were modified where necessary by the researchers and experts
5. Using the second-round scores to select only those indicators rated highly for validity and on which panel members had reached consensus. Indicators rated low or not reaching consensus among panellists were discarded.

After this second face-to-face consultation a draft set of quality indicators was produced (figure 1).

Phase 4: Developing and testing the draft quality indicator set in palliative practice

The next challenge was to test the draft indicator set in palliative care practice, in particular in order to assess its usability and feasibility (eg work load). Up until now, the draft set had been based on literature and expert opinion and hence needed operationalization and validation in practice, after which final adjustments could be made.

The indicators were transferred into questionnaires for patients, medical staff and next-of-kin (eg partner, relative or friend most closely involved) (table 3). In order to obtain all information needed to calculate the selected indicators we composed our questionnaires using previously validated questions from existing questionnaires when these existing questions covered the quality indicator well. We for instance used questions of the Views Of Informal Carers – Evaluation of Services (VOICES) Questionnaire (42;43) and the McGill Quality of Life Questionnaire (44), particularly as these questionnaires are frequently used and already validated for a large group of respondents. For those indicators where no validated questions were available we composed questions ourselves. In a pre-test among patients, family members and caregivers, we tested this not yet validated questions and made an estimation of the time needed to complete each questionnaire.When patients were not able to complete the questionnaire themselves, a proxy was assigned.

Table 3: distribution between observational units and study units during the testing phase

	Observational unit					
	Patient	Proxy	Next-of-kin	Caregiver		Care institution
Study unit	**before death**	**before death**	**after death**	**before death**	**after death**	**before death**
Care for the patient	x	x	x			
Care for the next of kin			x			
Process of care				x	x	
Structure of care						x

The questionnaires were divided over the observational units via four different palliative care services (representing all the different palliative care services in Flanders): the palliative home care team, the palliative care unit, the palliative support team in the hospital and the care home (only residents for whom a ‘palliative trajectory’ was initiated). A selection of services was recruited via the existing palliative care networks in Flanders: a call was sent out by the coordinators of these networks and services could volunteer to participate. After recruitment, a contact person for each service was appointed to organize the mailing of the questionnaires together with a researcher from the research team. The intention was to capture a cross section of the quality of palliative care in the different services at a particular moment, so one interrogation only was conducted. This demanded that a random selection was made of patients receiving palliative care services as well of those who had received palliative care services and had died between six weeks and six months earlier; a representative snapshot of the quality of existing care was thus created, taking into account coincidental patient mix confounders. With the quality of care susceptible to change over time, such a snapshot forms a basic starting point. The choice of a single measurement also makes the measurement of quality less burdensome for staff.

Four different types of questionnaire (available upon request), each measuring different quality indicators, were sent:

- for adult patients currently receiving palliative care
- for next-of-kin involved in the care of a patient who had died six weeks to six months previously
- for the central formal care provider (a nurse in the palliative home care team and in the care home and a nurse or a physician in the palliative support team and the palliative care unit) about the care of a patient currently receiving palliative care
- for general practitioner of patients who had died in the previous six weeks to six months

A maximum of 10 questionnaires was sent to any one nurse or physician.

We were able to list which patients, care providers and next-of-kin had already participated by the identifier numbers on the returned questionnaires attributed to each selected patient at the time of inclusion. In collaboration with the coordinator of each service involved, reminders were sent: one to patients and next-of-kin and up to two to care providers. As the researchers have not disposed of the list with patient, caregiver and family member contact details, identifying individuals through the identifier numbers on the questionnaires was not possible. After the reminders were sent and the questionnaires returned the collected data was analysed and quality indicators were calculated for each participating service.

The testing phase was then evaluated in terms of feasibility and usability. First telephone interviews with non-responding family members and family physicians were held to assess reasons for non-participation. This was done by a third independent party in order to preserve anonymity of patients and family members from the researchers. The contact person of the palliative service communicated the phone numbers of family and physicians directly to this independent person by email, based on the identifier numbers received by the researchers. Furthermore interviews were conducted with all coordinators and contact persons to evaluate the usability of the indicators and the procedure. Before the start of the interview all contact persons were asked to question the other caregivers about their experiences with the testing and the length of the questionnaire(s) they completed.

Based on the results of the test in terms of usability and feasibility, the indicator set, questionnaires and manual were adapted in order to be ready for use by the palliative services independently. We evaluated the instrument combining qualitative interviews with the caregivers involved about the workload and future use of the set and of quantitative psychometric analyses of the dataset gathered (e.g. number of missing answers per indicator). Furthermore, on request of the field, the indicator set was divided into a required minimal data set with complementary modules, each set usable separately or combined by the palliative services interested in quality measurement and improvement.

Discussion

This article presents a method followed in Flanders (the Flemish speaking part of Belgium) for developing quality indicators for palliative care. The method comprises four phases: 1) a literature review identifying existing quality indicators, 2) a literature review and expert consultation to identify the important themes and domains for quality palliative care, 3) quality indicator selection by expert consultation following the internationally validated RAND method and 4) testing the draft quality indicator set in practice. This four-phase method combines the different phases from previous development processes in other countries (ie literature review, expert consultation, practical test) and additionally includes patient and next-of-kin perspectives, structure, process and outcome indicators and applicability to all patients in all palliative care services.

The method developed here can contribute to the development of a standardized and functional set of quality indicators for palliative care in other countries as it meets the standards of scientific rigour and the level of comprehensiveness required.

Choosing a multi phased method leading to comprehensiveness

An important strength of the quality indicators development method described here is that it contains several phases to make the quality indicator set as comprehensive as possible, i.e. measuring quality of care for all adult palliative patients and across all domains relevant to palliative care. By combining a literature review on quality indicators with the building of a framework on important themes in palliative care, all aspects of palliative care have been taken into account. Previous sets of quality indicators for palliative care have tended to target specific populations such as cancer patients or vulnerable older people (9; 16; 18; 46-48). Our set, like that developed in the Netherlands is characterized by applicability to all setting and to all adult patient groups receiving palliative care (10) making it possible in the future, after assessing case mix adjusters, to compare scores of quality indicators not only over different disciplines but over different care settings.

Choosing a combination of evidence through literature review and expert consultation

As the thinking about quality indicators and the literature about quality of palliative care is developing quickly, it is necessary to review the field regularly, especially when beginning to develop a new set of quality indicators. In the literature we found researchers developing quality indicators who had not performed such a review but had started from an existing quality indicator set such as Saliba et al. (22) who had selected indicators feasible for nursing home quality assessment from the original ACOVE quality indicator set. This raises the question of whether completely new indicators need to be developed for a particular country or whether existing indicators can be adjusted and validated in a set for that country (37). Either way, a literature review can help to reveal existing indicators for further development and quality monitoring in any country.

Consultation of experts in palliative care in order to select the most important elements and indicators for measuring quality is a key element in the methodology described here and scoring by experts is important in assessing the validity and usefulness of the proposed indicators. Additionally it has the advantage that consultation of relevant palliative care actors enhances the acceptance and face-validity of the resulting indicator set among the palliative care community (10). The composition of the panel should reflect all relevant actors within palliative care: those in medical practice and palliative care, policymakers, researchers, patient representatives and family. The latter two categories are often forgotten in quality indicator development but are essential to the creation of a comprehensive set of quality indicators reflecting all perspectives in palliative practice. The expert consultation can best be done by the RAND/UCLA-method (42).

Choosing inclusion of outcome, process and structure indicators and involvement from all perspectives

Although measuring structure and process indicators from medical charts or administrative databases may be easier and cheaper, using only such sources for quality measurements may cause problems. Such databases can be limited, especially where indicators depend on precise documentation of issues such as communication, patient-reported outcomes or preferences (9); such information can only be obtained from patients and their families themselves. On the other hand some researchers and care providers tend to see quality only through the perspective of the patient. This perspective does indeed provide the best indication of whether good quality care has been achieved (10), but data for calculating have to be derived from individual care users which, apart from the practical issues, also limits the possibility of measuring all relevant aspects of the quality of palliative care which might be susceptible to improvement. Therefore many authors (9; 29; 35; 38; 39; 49) suggest that a quality indicator set, in order to be broad and comprehensive, must include structure and process as well as outcome indicators. We chose to translate our draft indicator set into questionnaires for the different respondent groups, patients, family and care providers, depending on which we considered would be the most reliable raters for selected quality indicators. Other quality researchers have based their evaluation of usability and feasibility on abstraction from patient records (11; 14; 23; 25), thereby automatically limiting the comprehensiveness of an indicator set.

Choosing a manageable testing of the quality indicator set

A crucial stage in the development process is the testing and evaluation of the set for usability and feasibility (eg work load) in practice; before it can be taken up on a nationwide scale the set needs operationalization and validation in palliative practice. Because of its extensive character, we felt it necessary to perform this testing phase in a small sample of palliative care service organisations.
To stimulate acceptance and use of quality indicators, stakeholders from palliative practice should be involved as early as possible in the development process. In Flanders we also collaborated closely with the Flemish Federation for Palliative Care, which helped to promote the project and enhance participation from care providers.

Work in progress

The quality indicator set for palliative care for adults in Flanders is now fully developed and ready to be used in practice to monitor quality of palliative care. Before scores of quality indicators can be validly compared across different services and care providers, however, significant case mix adjusters and the discriminative power of the indicators need to be assessed. Only if future research in a larger sample confirms the discriminative power of the indicators can they be recommended for comparative information or benchmarking (10) while benchmarking itself can only be made possible by implementing the quality indicator set on a large scale in Flanders.
A standardized method for the development of quality indicators for palliative care can also offer opportunities on the international level; providing internationally comparable data (50).

Conclusion

There is an increasing recognition of the need for quality indicators for palliative care in order to develop quality programmes across countries and to provide evidence to policymakers about the quality of the palliative care they are providing. However, a standardized method of developing quality indicators for palliative care has been lacking. In this paper we propose a method which meets the required level of scientific rigour and creates a sound basis for achieving the comprehensiveness needed in a set of quality indicators. The method suggested here combines standard literature analyses with multidisciplinary expert consultations involving all relevant actors within palliative care, following the RAND/UCLA-method, the only validated systematic method for quality indicator selection. Those wanting to develop indicators in other countries can use this standardized method to further develop and validate quality indicators for palliative care.

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PART III

Testing and fine-tuning the developed quality indicator set

Chapter 4

Quality indicators for palliative care services (Q-PAC): mixed-methods study testing for face validity, feasibility, discriminative power and usefulness

Kathleen Leemans, Luc Deliens, Anneke L. Francke, Robert Vander Stichele,
Lieve Van den Block, Joachim Cohen

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Abstract

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

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

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

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

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

Conclusion: Based on the results, minor adjustments were made to individual indicators, to the measurement tools and to the procedure used; the quality indicators are now ready for further evaluation and use across palliative care services in Belgium. As soon as these indicators are being used systematically it will be possible to demonstrate and compare quality at a national and international level and to evaluate improvement initiatives.

Introduction

Measuring how well palliative care services are succeeding in delivering high quality care requires systematic and continuous evaluation (1-5). Although previous initiatives to develop quality monitoring tools have been described in the literature, most of them have developed patient reported outcome measures meant to evaluate patient responses to treatment and not to evaluate and improve quality of care at the aggregate level of the service provider (1;6-10). To do so quality indicators, ie measurable aspects of care procuring improvement and transparency at aggregate level, need to be developed. In those projects that did develop quality indicators for palliative or end-of-life care, the focus is often on specific patient populations (11-19) or on specific dimensions of palliative care such as physical aspects (20;21). Structure and process indicators were mostly developed (11;12;20-24); the more recently sets developed contain outcome indicators only (3;25). The Council of Europe has stated a need for quality indicators for palliative care that assess all relevant dimensions and hence reflect the multidisciplinary character of palliative care (26).

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

Table 1: representation of the nine quality domains in the indicator set

Domain of quality palliative care	**N° of QI**
1. Physical treatment and care	12
2. Psychological, social and existential treatment and care	16
3. Information, communication , planning and decision making with patients	20
4. Information, communication , planning and decision making with family	6
5. Information, communication , planning and decision making with other caregivers	3
6. Type of care at the end of life	6
7. Coordination and continuity of care	9
8. Support of family and informal caregivers	9
9. Structure of care	4
TOTAL n° of QI	**85**

We followed a scientifically rigorous method combining evidence and consensus (figure 1), as suggested by Campbell et al. (2011) for the development of quality indicators (27). This method led to an indicator set of 85 indicators with good content validity as judged by an expert panel (28;29). A systematic literature review on existing quality indicators for palliative care and an article on the development process of the indicators have been published elsewhere (20;30).

Figure 1 Standardized method for comprehensive quality indicator development in palliative care

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

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

Methods

Design

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

Population and setting

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

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

- two mobile home teams
- two palliative care units
- two mobile hospital teams
- three care homes for older people

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

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

Questionnaires used to measure the quality indicators

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

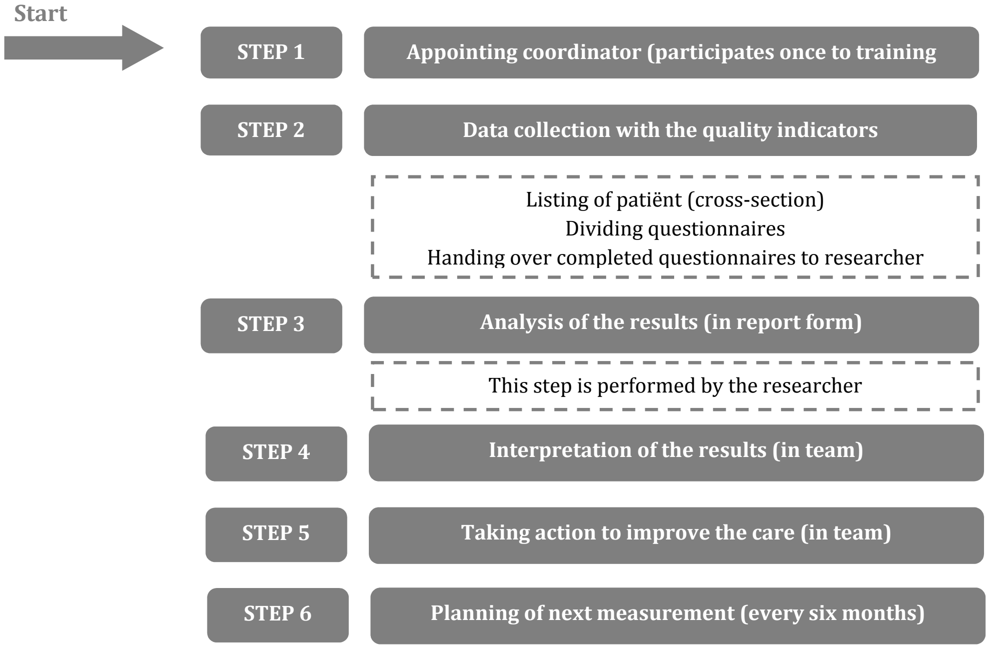
1) for the patients receiving care from the service, containing questions about the process and outcome of care
2) for the main professional caregivers of those patients (nurse, physician or psychologist of the team), containing questions about the process and outcome of care; to be completed while a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

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

Procedure

At the beginning of the feasibility study, a contact person was appointed from every service, responsible for supervision and communication within the service and distribution of the questionnaires during the whole study (figure 2). This person first selected both eligible groups of patients (those under care and those deceased between six weeks and six months previously) using a separate checklist listing all necessary contact details and socio-demographic characteristics. Then they distributed all questionnaires to the four different respondents and completed the service questionnaire. Lastly, one reminder was sent to non-responding patients and family carers and up to two to professional caregivers. Throughout the mailing procedure a manual explaining the procedure and operation of the quality indicator set was available. Before the start of the study, the cross-sectional measurement procedure was fine-tuned by an expert panel consisting of different stakeholders in palliative care (care providers, care users and policy makers) taking into account feasibility and workload.

Figure 2: schematic representation of measurement procedure of the quality indicators for palliative care



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

Qualitative evaluation

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

Measurements

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

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

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

Ethics

At inclusion, all respondents received a questionnaire and a covering letter signed by the coordinator of the service providing information about the purpose and the voluntary character of the study. Because the services were responsible for the distribution of the questionnaires and anonymous numbers were used for each participant, the completed questionnaires received by the researchers could never be linked to the identifying information and anonymity was preserved at all time. Informed consent of all patients, family members and caregivers was received. The protocol of the whole study was approved by the Ethical Review Board of Brussels University Hospital of the Vrije Universiteit Brussel (143201112708).

Results

During the feasibility study, 116 patients, 121 professional caregivers, 193 family carers and 192 physicians from all nine palliative care services met the inclusion criteria and received a questionnaire (table 3). The net response rate was 56% (n=64) for patients, 97% for caregivers (n=117), 56% for family carers (n=108) and 65% for physicians (n=125). Based on these response rates the feasibility of the measurement procedure can be evaluated as positive. Moreover during the interviews all contact persons except the ones from the palliative support teams in hospitals said they would use the instrument again in the future. To facilitate feasibility, they would prefer a shorter but still comprehensive version of the indicator set (ie a minimal set) if available. All contact persons declared that the time invested in the study was worthwhile. Only nine of the 116 participating patients and one of the family carers found that the time required to complete the whole questionnaire was too much. Furthermore they all evaluated the manual and checklists as clear and useful.

Table 3 Number included (participating) in the feasibility study

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

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

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

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

‡ 8 caregivers were excluded from the study: questionnaires were lost in mail

$ 1 physician was excluded from the study: not the treating physician of the deceased patient

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

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

	Rater	Indicator title
1	Ca	Percentage of patients who were subjected to a general symptom assessment on a validated scale
2	Ph	Percentage of patients whose symptom burden was mostly or completely under control in the final week of life
3	Ca	Percentage of patients who were subjected to a pain assessment, with or without pain scale
4	Ca	Percentage of patients who were subjected to a delirium assessment, with or without delirium scale
5	Ca	Percentage of patients who were subjected to an anxiety assessment, with or without anxiety scale
6	Pa	Percentage of patients who were most of the time or always treated for pain
7	Pa	Percentage of patients who were most of the time or always guided for anxiety
8	Ca	Percentage of patients treated for delirium
9	Pa	Percentage of patients who, after treatment, experienced significant improvement in pain
10	Pa	Percentage of patients who, after treatment, experienced significant improvement in anxiety*
11	Ca	Percentage of patients for whom the delirium improved substantially or completely after the treatment
12	Fc	Percentage of patients for whom the delirium improved sufficiently after the treatment (family carers)
13	Ca	Percentage of patients whose shortness of breath was relieved within 48 hours after admission or starting palliative care[†]
14	Pa	Percentage of patients with a score of 3 or less on a scale of 0 to 10 (average over 3 days) for pain
15	Pa	Percentage of patients with a score of 3 or less on a scale of 0 to 10 (average over 3 days) for anxiety
16	Fc	Percentage of family carers who indicated that caregivers were most of the time or always attentive to their anxiety and despondency
17	Pa	Percentage of patients who indicated that the caregivers were most of the time or always attentive to their personal situation and needs
18	Pa	Percentage of patients who indicated that the caregivers regularly assessed how they were feeling
19	Pa	Percentage of patients who indicated that the caregivers regularly talked to them about spirituality and religion in an understanding way[‡]
20	Fc	Percentage of family carers who indicated that the caregivers regularly talked to them about what it meant to them to care for their ill next of kin
21	Fc	Percentage of family carers who indicated that the caregivers regularly asked how they were feeling
22	Fc	Percentage of family carers who indicated that the caregivers regularly talked to them about spirituality and religion in an understanding way[‡]
23	Pa	Percentage of patients with a score of 5 or more on a scale of 0 to 10 for psychological wellbeing[$]
24	Pa	Percentage of patients with a score of 5 or more on a scale of 0 to 10 for social well-being[$]

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

	Rater	Indicator title
25	Pa	Percentage of patients with a score of 5 or more on a scale of 0 to 10 for spiritual well-being$
26	Pa	Percentage of patients with a score of 5 or more on a scale of 0 to 10 for quality of life$
27	Pa	Percentage of patients who were most of the times or always offered counselling when they were not feeling well or feeling less well
28	Fc	Percentage of family carers who were most of the time or always offered counselling when they were not feeling well or feeling less well
29	Pa	Percentage of patients who indicated that they could most of the time or always be alone and talk to someone undisturbed if wanted
30	Pa	Percentage of patients who indicated that the caregivers most of the times or always respected their personal wishes and that they could most of the time or always plan their day and decide about the care provided
31	Pa	Percentage of patients who were most of the time or always able to have some privacy with their family carers if wanted
32	Pa	Percentage of patients who indicated that most or all of their caregivers respected their philosophy of life
33	Fc	Percentage of family carers who indicated that most or all of the caregivers respected their philosophy of life
34	Pa	Percentage of patients who indicated that a priest or spiritual counsellor was available*

Pa = patient   Ca = caregiver   Fc = family carer   Ph = physician

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

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

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

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

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

	Rater	Indicator title
1	Pa	Percentage of patients who received the right amount of information about their diagnosis*
2	Pa	Percentage of patients who received the right amount of information about their prognosis*
3	Pa	Percentage of patients who received the right amount of information about the course of the disease*
4	Pa	Percentage of patients who received the right amount of information on the advantages and disadvantages of treatments*
5	Pa	Percentage of patients who received the right amount of information on palliative care options*
6	Fc	Percentage of family carers who received sufficient information about palliative lump sum and palliative leave
7	Fc	Percentage of family carers who received the right amount of information about the patient's condition and treatments
8	Fc	Percentage of family carers who received the right amount of information about the patient's approaching death
9	Fc	Percentage of patients who received the right amount of information about the treatment or end-of-life decision they requested
10	Fc	Percentage of patients (or family carers in case the patient lacked capacity) who were sufficiently informed when a treatment or end-of-life decision was taken†
11	Pa	Percentage of patients who indicated that they most of the time or always received clear and comprehensible and never or sometimes contradictory information
12	Fc	Percentage of family carers who received clear and comprehensible and non-contradictory information about the patient’s approaching death
13	Pa	Percentage of patients who indicated that they discussed their wishes about care objectives with a physician (to patient)*
14	Ph	Percentage of patients with whom the physician discussed the care objectives (to physician)
15	Ca	Percentage of patients about whom multidisciplinary consultations took place at least once a week about their care objectives
16	Ca	Percentage of patients whose family physician was regularly or always involved in these multidisciplinary consultations‡
17	Ca	Percentage of patients about whom a conversation about their care preferences took place between the caregivers and family carers in the first week after admission or start of palliative care
18	Fc	Percentage of patients whose authorized representative was involved when the patient lost capacity
19	Pa	Percentage of patients who are not receiving treatments they do not want*
20	Pa	Percentage of patients who are not receiving drugs they do not want*
21	Ph	Percentage of patients who were not started on artificial fluids and/or nutrition in the last month before death

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

	Rater	Indicator title
22	Fc	Percentage of patients for whom starting or terminating administration of artificial fluids and/or nutrition was discussed with family carers
23	Ca	Percentage of patients whose wishes on resuscitation (DNR- code) are known to the caregivers‡
24	Ca	Percentage of patients who were asked how they felt about end of life decisions and euthanasia
25	Fc	Percentage of patients who got a positive response to (all) their request(s) for a treatment or an end-of-life decision
26	Fc	Percentage of patients who were involved in the final treatment or end-of-life decision (after a request by the patient)
27	Fc	Percentage of patients (or family carers in case the patient lacked capacity) who were involved in the treatment or end-of-life decision (without a request by the patient)†

Pa = patient   Ca = caregiver   Fc = family carer   Ph = physician

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

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

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

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

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

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

	Rater	Indicator title
18	Pa	Percentage of patients who most of the time or always felt they were given continuous care by their various caregivers
19	Pa	Percentage of patients who mostly or entirely knew who to talk to about their care
20	Se	Percentage of services that have a guideline on requests for euthanasia
21	Se	Percentage of services that have a 'care for the carer' policy
22	Se	Percentage of services with a policy allowing unlimited visits of family carers and friends to terminal patients
23	Se	Percentage of services offering comfortable accommodation to the patient's family carers

Pa = patient Ca = caregiver Fc = family carer Ph = physician Se = service

* These indicators origin of Earle et al. (2005) and were measured ‘in the last 30 days of life’. In this form, the indicators showed problems with usefulness: they did not measure the quality of care provided by the service. Therefore ‘in the last 30 days of life’ was replaced by ‘since admission or start of palliative care’.

Decisions and adjustments based on the results of the feasibility study

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

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

The final Q-PAC quality indicator set now consists of 84 indicators in three modules. In this article we only present the indicator titles per module in tables 4, 5 and 6. Changes as compared with the original indicators are described in the footnote of the tables.

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

Example 1: Percentage of patients for whom a priest or spiritual counselor is available (bio-psycho-social-spiritual module)	
Numerator	Number of patients for whom a priest or spiritual counselor is available
Denominator	Total number of patients for whom this indicator was measured
Question	Is there a spiritual or moral consultant available for you to consult? (patient) ☐ Yes ☐ No
Evaluation	Problems with feasibility: 15% of patients did not answer the question
Adjustment	We changed the answering categories: Is there a spiritual or moral consultant available for you to consult? ☐ Yes, available ☐ Yes, but I don't need to consult him ☐ No, not available
Example 2: Percentage of patients for whom the family physician was involved in the multidisciplinary meetings (communication and care planning module)	
Numerator	Number of patients for whom the family physician often or every time was involved in the multidisciplinary meeting
Denominator	Total number of patients for whom the indicator was measured
Question	Was the family physician involved at these multidisciplinary meetings? (caregiver) ☐ Yes, every time ☐ Yes, often ☐ Yes, sometimes ☐ No, never
Evaluation	Problems with usefulness: the contact persons of the palliative care units and mobile support teams (hospital) did not find this indicator useful for their service
Adjustment	We decided to keep the indicator in its original form for all services because of its importance. Palliative care units and palliative support teams will score lower on this indicator than the other services, but that will be compensated by taking into account case mix adjusters and by setting the right norms for these types of services.
Example 3: Percentage of patients for whom no new course of chemotherapy was started in the last month of life (coordination and circumstances surrounding death module)	
Numerator	Number of patients for whom no new course of chemotherapy was started in the last month of life
Denominator	Total number of cancer patients
Question	When was this patient for the last time started on a new course of chemotherapy? (physician) ☐ (mm/dd/yyyy) ☐ I don't know ☐ Not applicable
Evaluation	Problems with usefulness: this indicator does not measure the quality of care provided by the service
Adjustment	We changed the indicator title and numerator so that the indicator measures the quality of care provided by the service: Title: Percentage of patients for whom no new course of chemotherapy was started *since the start of palliative care* Numerator: Number of patients for whom no new course of chemotherapy was started *since the start of palliative care*

Discussion

In this study, we evaluated a quality indicator set designed to measure the quality of care delivered by palliative care services in Belgium. Caregivers in the palliative care services confirmed the face validity of the indicator set ie that it covers the aspect that it purports to evaluate; response rates from patients, family carers and professional caregivers were high and the measurement procedure was evaluated as feasible by the caregivers; hence the developed quality indicators were found to be valid, feasible, discriminative and useful. This implies that the Q-PAC quality indicators are ready to be used in palliative care services in Belgium in order to further validate and implement the indicators and at long last to monitor the quality of palliative care for patients and their families.

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

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

Our study resulted in some adjustments to the individual quality indicators and it also indicated the need to modify the measurement procedure based on the factors that influence the measurements. Although most services were positive and said they would use the indicators in the future, there were some problems with the palliative support teams in hospitals. Few patients were eligible for inclusion while they were still alive and fewer family carers returned a completed questionnaire than did participants from the other services. One explanation could be that because the mobile support teams function as a support for the treating physicians on several hospital wards, family carers were not always aware of what they did and sometimes did not know that the patient had been seen by them. Additionally, mobile palliative support teams in hospitals often chose not to deliver a questionnaire to eligible patients or their proxies because they considered it would be a psychological burden to them. The number of patients currently receiving support was also relatively small in the individual support teams, care homes and, to a lesser extent, in the palliative care units in hospitals. A larger number would be needed for monitoring within one specific service, preferably at least ten patients per service. We therefore propose an additional inclusion period for patients under guidance of the service order to increase the numbers and hence the reliability of the results. Further decisions on adjusting the measurement procedure will be made together with some experts in the field.
In the future, palliative care services will be invited to work voluntarily with the quality indicators to monitor their practice, the intention being that voluntary rather than obligatory use of the indicators will mean that caregivers will apply the quality information in a more considered manner. They will be recommended to measure quality indicators twice a year in order to see what aspects of care are going well and which need improvement. However, our qualitative evaluation in conjunction with the users showed that they would prefer a more limited but still comprehensive set of quality indicators rather than the whole set. Such a minimal set should incorporate core indicators over the three modules, with optional thematic modules that they can choose to measure alternately to evaluate aspects of their functioning. This would reduce the length of the questionnaires for all respondents and the work-load for the caregivers and should lead to more palliative care services being willing to measure quality indicators leading to systematic monitoring on a national level.

Conclusion

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

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Chapter 5

RAND/UCLA expert consultation for selection of a minimal set of quality indicators for palliative care

Kathleen Leemans, Luc Deliens, Lieve Van den Block, Robert Vander Stichele,
Anneke L. Francke, Joachim Cohen

Submitted

Abstract

Background: A feasibility evaluation of quality indicators for palliative care identified the need for a minimal but comprehensive indicator set to monitor quality of palliative care services with a limited workload for the team and short questionnaires for the patients, caregivers and family carers.

Objectives: To select this set using a modified RAND/UCLA expert consultation.

Design: A two round modified RAND panel.

Setting/subjects: 13 experts in palliative care (professionals and patient representatives).

Measurements: In a home assignment experts were asked to score 80 developed indicators for ‘priority’ to be included in the minimal set on a scale from 0 (lowest priority) to 9 (highest priority). The second round consisted of a plenary meeting in which the minimal set was finalized.

Results: Thirty-nine of the 80 indicators were discarded while 19 were definitely selected after the home assignment and 22 were proposed for discussion during the meeting; twelve of these survived the selection round. The final minimal indicator set for palliative care consists of five indicators about the physical aspects of care, six about the psychosocial aspects of care, 13 about information, communication and care planning, five about type of care and two about continuity of care.

Conclusion: A minimal set of 31 indicators reflecting all the important issues in palliative care was created for palliative care services to assess the quality of their care in a quick and efficient manner. Additional topic-specific optional modules are available for more thorough assessment of specific aspects of care.

Introduction

Quality of care is of interest to everyone receiving or providing palliative care (PC) (1). With a growing culture of assessment in PC, one of the greatest challenges for specialized PC services is to evaluate their care systematically in order to improve it at the level of patients and their families (2-5). Quality indicators, ie measurable aspects of care addressing a specific aspect of care, can be a helpful tool in achieving improvement and transparency at aggregated service level (6-9). A number of quality indicators of palliative or end-of-life care have previously been developed (10;11). However, these often focus only on cancer patients or on specific dimensions for palliative care such as physical aspects of care (12-19). The Council of Europe has stated a need for quality indicators for palliative care that assess all relevant dimensions and hence reflect the multidisciplinary character of palliative care (20).

Therefore we developed a comprehensive quality indicator set for palliative care in Belgium. We followed a scientifically rigorous method combining evidence and consensus (figure 1) as suggested by Campbell et al. (2011) for the development of quality indicators (21), including a systematic review on existing quality indicators of palliative care and a rigorous methodology to develop the quality indicator set, both of which are published elsewhere (10;22).

Figure 1 Standardized method for comprehensive quality indicator development in palliative care

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

The set was developed to evaluate comprehensively the quality of care for all patients making use of a specialized palliative care service, which in Belgium includes multidisciplinary palliative home care teams, palliative care units and multidisciplinary palliative support teams in hospitals. To ensure comprehensiveness, we wanted the indicator set to evaluate quality across nine broad domains of palliative care (table 1). As a result, the indicator set was partly composed of existing (validated) international indicators retrieved from the systematic literature review (for domains and themes that were already covered) and indicators developed within the expert panel (for domains and themes that were not yet covered by existing indicators). Furthermore we aimed to include structure, process and outcome indicators, as is deemed appropriate when monitoring overall quality of care (23;24). The comprehensiveness of the set implied that quality of care had to be measured prospectively (for living patients) and retrospectively (for patients who have died) in order to monitor aspects of quality of palliative care, but also terminal care (final days and hours) and aftercare for family members. Hence, in order to gather all the information necessary to calculate the indicators, the different indicators were operationalized into five different questionnaires: 1) for living patients (or a proxy) receiving care from a specialized palliative care service, 2) for the most involved professional caregiver of these patients (nurse, physician or psychologist of the team), 3) for bereaved family members of patients who died under care of a specialized palliative care service, 4) for the most involved caregiver of these patients (nurse, physician or psychologist of the team), 5) for the coordinator of the team (one-time only questionnaire for the structure indicators). Existing questions of validated questionnaires were used where possible and these were combined with questions developed by the researchers and the expert panel for those indicators where no validated questions were available or deemed appropriate. A feasibility testing of the resulting comprehensive quality indicator set in nine specialized palliative care services indicated the length of the questionnaires as a feasibility issue (25). A remaining challenge was therefore to provide palliative care services with a minimal (limiting the work-load, overload of information and the length of the questionnaires) yet comprehensive set (still covering all domains of palliative care).

Table 1 Overview of representation of domains of quality of care in the comprehensive and minimal indicator set

	Number of indicators		
Domains for quality of palliative care	**CS**	**R1**	**MS**
1. Physical aspects of care	11	5	5
2. Psycho-social and spiritual aspects of care*	16	1	3
3. Communication and care planning with patient*	20	4	7
4. Communication and care planning with family	6	2	3
5. Communication and care planning among caregivers*	3	0	1
6. Type of care and circumstances surrounding death	6	2	5
7. Coordination and continuity of care	9	3	3
8. Care for family*	9	2	4
TOTAL	**80**	**19**	**31**

CS = Complete set R1 = round 1 of the RAND/UCLA panel (home assignment) MS = minimal set
* This domain was underrepresented in the provisional selection of the minimal set after round 1 (home assignment)

The aim of the current study was to trim this comprehensive set to a minimal indicator set for quicker and more efficient assessment while still covering all elements inherent to palliative care. This paper therefore presents the final step in the quality indicator tool development for palliative care in Belgium: selecting and presenting a minimal comprehensive quality indicator set for quick and efficient quality monitoring in palliative care services, using a strong methodological design.

Methods

Design

A two round modified RAND/UCLA (Research ANd Development corporation in collaboration with the University of California at Los Angeles) panel was conducted in order to trim a previously developed comprehensive quality indicator set to a minimal set. This method is a systematic and appropriate approach that can be used to determine the extent of agreement among experts on a specific issue and is particularly useful in developing and identifying quality indicator sets (25). It combines scientific evidence, in this case the previously developed and tested indicator set, with consensus among experts in the field (26). At first the experts are assigned a home assignment to preliminarily score the indicators on priority (in this case to be part of a minimal set for palliative care); then a plenary discussion takes place to reach consensus on the final selection of indicators.

Participants

The panel was composed of experts in the field of palliative care (PC) in Belgium. They were recruited from three areas: PC researchers, PC providers and PC users. We balanced the number of experts per area according to the importance of that area (see box 1). In total 13 experts participated: one researcher, four physicians, four nurses, two psychologists, one volunteer and one representative of a patient organization.

Box 1 Participants in the expert consultation

Area	Profession	Number	Round 1	Round 2
1. Palliative care research	researcher	1	1	1
2a. Multidisciplinary palliative home care team	physician	2	2	1
	nurse	1	1	1
	psychologist	1	1	1
2b. Palliative care unit	nurse	2	2	2
2c. Palliative support team	physician	2	2	2
	nurse	1	1	1
	psychologist	1	1	1
3. Patient/family perspective	volunteer	1	1	0
	patient organization	1	1	0
	TOTAL	**13**	**13**	**11**

Rating process

As the selection of a minimal indicator set was needed to shorten the questionnaires used to gather all necessary data, we decided to limit four types of questionnaires (for patients, professional caregivers, family carers and physicians) to a maximum of eight indicators per questionnaire. In this way all relevant perspectives were still covered. The length of each questionnaire would then correspond to one page, which the caregivers found feasible for all respondents. The palliative care team questionnaire including the four structure indicators was kept in its original form. Hence, out of the list of 80 process and outcome indicators a maximum of 32 (eight per respondent type) could be selected.

One month before the meeting, the panel members received a list of 80 process and outcome quality indicators (excluding the four structure indicators), with descriptions of each indictors nominator, denominator and measurement questions accompanied by a clear assignment and a document explaining the background and purpose of the project. The list with indicators was presented per questionnaire respondent type (ie patient, professional caregiver, family carer and physician) to give the experts a clear overview of the selection they had to make. The experts were asked to score each indicator for priority to be included in the minimal indicator set on a scale from 1 to 9, with 1 equaling 'lowest priority' and 9 equaling 'highest priority'. Furthermore they were asked to choose the eight indicators with highest priority per questionnaire respondent type. The panel members returned their score sheets to the researcher so that all scores could be processed before the discussion meeting.

Analysis

For each indicator the researcher calculated the median score and the number of times the experts marked it with 'highest priority'. The RAND/UCLA method prescribes that indicators with a median score of 7, 8 or 9 on which consensus was reached (ie no more than two experts scored the indicator with a 1, 2 or 3), are retained immediately; indicators with a median score of 1, 2 or 3 on which consensus was reached (ie no more than two experts scored the indicator 7, 8 or 9) are discarded immediately; all other indicators, ie those on which consensus was not reached and those with a median score of 4, 5 and 6, are discussed with all experts during the meeting in order to reach consensus on the final selection. Following this method, 67 of the 80 indicators would have been retained immediately, exceeding the target number of 32. We therefore applied a stricter selection method: only the indicators with a median score of 7, 8 or 9 on which consensus was reached and marked by seven or more panel members with 'highest priority' were immediately selected for the minimal set. Indicators with a median score of 6 or less were definitely discarded. All other indicators scoring high (7, 8 or 9) but on which consensus was not reached or was marked by no more than six panel members with 'highest priority' were discussed during the meeting.

Plenary discussion meeting

During a one-day discussion meeting the selection method and results of the home assignment were presented to the experts. At the beginning of the meeting the experts received the list of all 80 indicators presenting per indicator the median score, the number of times marked with 'highest priority' and the category they belonged to (discarded, selected, to be discussed). The researcher presented per questionnaire respondent type which indicators were already selected for the minimal set and which still needed to be discussed and decided on. In order to preserve the eight domains in the minimal set, we informed the panel members which domains were yet underrepresented; they could take this into account though they were not obliged to select the indicators to complete the domains.

Ethical concerns

Because no patient and care data were used in this study no ethical approval was required. In the recruitment letter for the experts, the confidentiality and anonymity of the research findings were guaranteed. As no personal information was collected from the experts, no informed consent was requested.

Results

In total, 13 experts participated in the study (box 1). All experts completed the home assignment; 11 of them were present at the plenary discussion meeting. Based on the first scoring round of the home assignment, 39 indicators were discarded immediately (consensus over low priority), 19 were selected immediately (consensus over highest priority) and 22 had to be discussed (no consensus). Of those, 13 could still be selected (in order not to exceed the targeted maximum of 32 indicators). Three of the eight original domains in the original quality indicator set were at this point underrepresented in the provisional selection for the minimal set: psycho-social-spiritual aspects of care, communication and care planning with the patient and amongst professional caregivers and care for the family (table 1). At the end of the discussion the minimal set for home and hospice PC in Belgium consisted of 31 indicators: five about physical aspects of care, three about the psycho-social-spiritual aspects, 11 about information, communication and care planning, five about type of care, three about continuity of care and four about care for family. Hence the minimal set covers all the original quality domains. An elaborated presentation of the minimal set including nominator, denominator, question and domain can be found in table 2.

Table 2 Presentation of the minimal indicator set for palliative care in Belgium

	Rater	Indicator description	Measurement question	Evidence of the indicator*
		1. *Physical aspects of care*		
1	Ca	Nominator: number of patients who were subjected to a general symptom assessment on a validated scale Denominator: total number of patients for whom this indicator was measured	Have you or any other carer evaluated the patient's symptom burden since the admission or start of palliative care? ☐ Yes, with a scale ☐ Yes, without a scale ☐ No	Indicator developed by the researchers together with an expert panel Measurement question developed by the researchers together with an expert panel
2	Ph	Nominator: number of patients whose symptom burden was mostly or completely under control in the final week of life Denominator: total number of patients for whom a palliative care service was involved for at least 3 days	Did you have the feeling that the patient's symptom burden (such as pain, anxiety, shortness of breath ...) was under control in the last week before death? ☐ Yes, totally ☐ Yes, largely ☐ No, not totally ☐ No, totally not ☐ I don't know.	Indicator from Peruselli (1997): 'Symptom control in the last week of care' Measurement question by the researchers together with an expert panel
3	Ca	Nominator: number of patients who were subjected to a pain assessment, with or without pain scale Denominator: total number of patients for whom this indicator was measured	Have you or any other carer measured the patient's pain since the admission or start of palliative care? ☐ Yes,with a pain scale ☐ Yes,without a pain scale ☐ No	Modified indicator from Twaddle (2007): 'pain measurement within 48 hours after admission' Measurement question developed by the researchers together with an expert panel

Table 2 Presentation of the minimal indicator set for palliative care in Belgium - continued

	Rater	Indicator description	Measurement question	Evidence of the indicator*
4	Pa	Nominator: number of patients who, after treatment, experienced significant improvement in pain Denominator: total number of patients treated for pain	In your opinion, did the treatment adequately relieve the pain? □ Yes, □ No	Modified indicator from Keay (1994): 'If patient had pain, this is followed to assess results of intervention and pain is reduced' Measurement question developed by the researchers together with an expert panel
5	Ca	Nominator: number of patients whose shortness of breath was relieved within 48 hours after admission or starting palliative care Denominator: total number of patients with shortness of breath	Was the patient suffering from shortness of breath at the time of admission or when palliative care was started? □ Yes □ No Did you or any other carer take action to relieve this patient's shortness of breath after admission or after starting palliative care? □ Yes, □ No How long after the patient was admitted or after palliative care was started was a relief of the shortness of breath achieved? □ (hours-days) □ No relief was achieved	Indicator from Twaddle (2007): 'Shortness of breath relieved within 48 hours after admission' Measurement questions developed by the researchers together with an expert panel
		2. Psycho-social aspects of care		
6	Pa	Nominator: number of patients who indicated that the caregivers regularly assessed how they were feeling Denominator: total number of patients for whom this indicator was measured	Have your carers checked how you are feeling? □ Yes, regularly □ Yes, once □ No	Indicator developed through expert panel Measurement question developed by the researchers together with an expert panel

Table 2 Presentation of the minimal indicator set for palliative care in Belgium - continued

	Rater	Indicator description	Measurement question	Evidence of the indicator*
7	Pa	Nominator: number of patients with a score of 5 or more on a scale of 0 to 10 for quality of life Denominator: total number of patients for whom this indicator was measured	When you consider all aspects of your life - physical, psychological, social, spiritual, existential and financial - your quality of life over the past 2 days was: (very bad) 0 --------------------- 10 (excellent)	Indicator developed through expert panel Measurement question of 'McGill quality of life questionniare'
8	Pa	Nominator: number of patients who indicated that the caregivers most of the times or always respected their personal wishes and that they could most of the time or always plan their day and decide about the care provided Denominator: total number of patients for whom this indicator was measured	Do your carers give you the freedom to plan your day? ☐ Never ☐ Sometimes ☐ Usually ☐ Always ☐ Not applicable. Can you co-decide about your care? ☐ Never ☐ Sometimes ☐ Usually Do your carers take your personal wishes into account? ☐ None of them do ☐ Some of them do ☐ Most of them do ☐ All of them do	Indicator from Claessen (2009): 'extent to which patients experience respect for their autonomy' Measurement questions from Claessen (2009)
		3. Communication and care planning with patient		
9	Pa	Nominator: number of patients who received the right amount of information about their diagnosis Denominator: total number of patients for whom this indicator was measured	Are you getting enough information about the diagnosis? ☐ less than necessary ☐ just the right amount ☐ more than enough	Modified indicator from Claessen et al. (2009): 'extent to which patients receive information about the expected course of the illness' Modified measurement question from Claessen et al. (2009)

Table 2 Presentation of the minimal indicator set for palliative care in Belgium - continued

	Rater	Indicator description	Measurement question	Evidence of the indicator*
10	Pa	Nominator: number of patients who received the right amount of information about the course of the disease Denominator: total number of patients for whom this indicator was measured	Are you getting enough information about the course of the disease? ☐ less than necessary ☐ just the right amount ☐ more than enough	Modified indicator from Claessen et al. (2009): ‘extent to which patients receive information about the expected course of the illness’ Measurement question from Claessen et al. (2009)
11	Pa	Nominator: number of patients who received the right amount of information on palliative care options Denominator: total number of patients for whom this indicator was measured	Are you getting enough information with regard to end-of-life care? ☐ less than necessary ☐ just the right amount ☐ more than enough	Modified indicator from Claessen et al. (2009): ‘extent to which patients receive information about the advantages and disadvantages of various types of treatments’ Modified measurement question from Claessen et al. (2009
12	Pa	Nominator: number of patients who indicated that they most of the time or always received clear and comprehensible and never or sometimes contradictory information Denominator: total number of patients for whom this indicator was measured	Do your carers explain things to you understandably? ☐ Never ☐ Sometimes ☐ Usually ☐ Always Do your carers give you conflicting information? ☐ Never ☐ Sometimes ☐ Usually ☐ Always	Modified indicator from Claessen et al. (2009): ‘extent to which patients indicate that they receive understandable explanations’ and ‘extent to which patients indicate that they receive contradictory information’ Measurement questions from Claessen et al. (2009)

Table 2 Presentation of the minimal indicator set for palliative care in Belgium - continued

	Rater	Indicator description	Measurement question	Evidence of the indicator*
13	Ph	Nominator: number of patients with whom the physician discussed the care objectives Denominator: total number of patients for whom this indicator was measured	Have you ever talked to the patient about his or her wishes with regard to the care objectives? □ Yes, once □ Yes, several times □ No □ I don't know	Indicator developed by researchers in cooperation with expert panel Measurement questions developed by the researchers together with an expert panel
14	Ca	Nominator: number of patients (or representatives) who were asked how they felt about end of life decisions and euthanasia Denominator: total number of patients for whom this indicator was measured	Have you or another carer inquired about the patient's opinion with regard to end-of-life decisions? □ Yes, □ No Have you or another carer asked the patient's opinion with regard to euthanasia? □ Yes, □ No	Indicator from Claessen et al. (2009): 'Extent to which relatives indicate that the patient was asked about her/his opinions with regard to end-of-life decisions' Measurement questions from Claessen et al. (2009)
15	Fc	Nominator: number of patients who got a positive response to (all) their request(s) for a treatment or an end-of-life decision Denominator: number of patients who requested a treatment or an end-of-life decision	Indicate about which of the following treatment decisions your relative asked the doctor or another carer a question. □ Discontinuing a life-prolonging treatment □ Increasing pain medication with a potentially life-shortening effect □ Administering medication with the intention of rendering your relative unconscious (palliative sedation) □ Administering life-ending drugs on your relative's own explicit request (euthanasia) □ None of the above decisions Did the carers take each of these questions about a treatment decision seriously? □ Yes, □ No	Indicator developed through an expert panel Measurement questions developed by the researchers together with an expert panel

Table 2 Presentation of the minimal indicator set for palliative care in Belgium - continued

	Rater	Indicator description	Measurement question	Evidence of the indicator*
		4. Communication and care planning with family		
16	Fc	Nominator: number of family carers who received the right amount of information about the patient's condition and treatments Denominator: total number of family carers for whom this indicator was measured	Did you receive information about your relative's condition? □ less than needed □ the right amount more than needed Did you get information about the pros and cons of different treatments? □ less than necessary □ just the right amount □ more than enough	Indicator from Finlay (2008): 'providers keep family informed about the patient's condition and treatment' Modified measurement questions of Claessen (2009)
17	Fc	Nominator: number of family carers who received the right amount of information about the patient's approaching death Denominator: total number of family carers for whom this indicator was measured	Did you get information about the impending death? □ less than necessary □ just the right amount □ more than enough	Modified indicator from Miyashita (2008): 'explanation to family of patient's impending death' Measurement question of Claessen (2009)
18	Ca	Nominator: number of patients about whom a conversation about their care preferences took place between the professional caregivers and family carers in the first week after admission or start of palliative care Denominator: total number of patients for whom this indicator was measured	How long after admission or after palliative care was started, did the carers and family have a conversation about the patient's care preferences? □ (hours - days) □ No conversation has taken place (yet) with the family about the care preferences	Modified indicator from Twaddle (2007): 'a conversation takes place with the family about the patient in the hospital to decide on the care preferences' Measurement questions developed by the researchers together with an expert panel

Table 2 Presentation of the minimal indicator set for palliative care in Belgium - continued

	Rater	Indicator description	Measurement question	Evidence of the indicator*
		5. Communication and care planning among professional caregivers		
19	Ca	Nominator: number of patients about whom multidisciplinary consultations took place at least once a week about their care objectives Denominator: total number of patients for whom the palliative care service was involved for at least 1 week	How often, in the past month, was a formal multidisciplinary consultation meeting held for this patient between carers to discuss the care objectives and/or options in terms of palliative care? ☐ once ☐ Less than once a week ☐ Approximately once a week ☐ Almost daily ☐ No formal multidisciplinary meetings have taken place (yet)	Indicator developed through an expert panel Measurement questions developed by the researchers together with an expert panel
		6. Type of care and circumstances surrounding death		
20	Fc	Nominator: number of patients who scored 5 or more on a scale of 0 – 10 for the quality of death according to family carers Denominator: total number of patients for whom this indicator was measured	Please indicate on a scale from 0 to 10 how you perceived your relative's death? (restless death) 0 ------------10 (peaceful death)	Indicator developed by the researchers together with an expert panel Measurement question developed by the researchers together with an expert panel
21	Ph	Nominator: number of patients who scored 5 or more on a scale of 0 – 10 for the quality of death according to physicians Denominator: total number of patients for whom this indicator was measured	Please indicate on a scale from 0 to 10 how you perceived the patient's death? (restless death) 0 -------------- 10 (peaceful death)	Indicator developed by the researchers together with an expert panel Measurement question developed by the researchers together with an expert panel

Table 2 Presentation of the minimal indicator set for palliative care in Belgium - continued

	Rater	Indicator description	Measurement question	Evidence of the indicator*
22	Ph	Nominator: number of patients whose palliative care started at least 2 weeks before death Denominator: total number of patients for whom this indicator was measured	When did you start the palliative care for this patient? □ (dd/mm/yyyy) □ I don't know. When did this patient start receiving support from the palliative team? *(only if the respondent is the family physician)* □ (dd/mm/yy) □ I don't know	Modified indicator from Peruselli (1997): 'the palliative care services respond rapidly to the request of care' Measurement questions developed by the researchers together with an expert panel
23	Ph	Nominator: number of patients admitted more than once to the emergency room since admission or start of palliative care Denominator: total number of patients for whom this indicator was measured	Was this patient admitted to the emergency department more than once since admission or since the start of the palliative care? □ Yes □ No □ I don't know	Modified indicator from Earle (2006): 'proportion with more than one emergency room visit in the last 30 days of life' Measurement questions developed by the researchers together with an expert panel
24	Ph	Nominator: number of patients admitted to the intensive care unit since admission or start of palliative care Denominator: total number of patients for whom this indicator was measured	Was this patient ever taken to intensive care since admission or since the start of the palliative care? □ Yes, □ No □ I don't know.	Modified indicator from Earle (2006): 'proportion admitted to the ICU in the last 30 days of life' Measurement questions developed by the researchers together with an expert panel

Table 2 Presentation of the minimal indicator set for palliative care in Belgium - continued

	Rater	Indicator description	Measurement question	Evidence of the indicator*
		7. Coordination and continuity of care		
25	Ph	Nominator: number of patients who were in touch with their family physician on a weekly basis in the last 3 months before death (personally or by telephone) Denominator: total number of patients for whom this indicator was measured	Did you have contact with the patient in the last 3 months of his/her life? ☐ Yes, by telephone ☐ Yes, in person ☐ Yes, both by telephone and in person ☐ No How often did you see or hear from the patient in those last 3 months? ☐ Every day ☐ A few times a week ☐ Every week ☐ Every month ☐ Less than once a month ☐ I don't know	Indicator developed by the researchers together with an expert panel Measurement question developed by the researchers together with an expert panel
26	Ca	Nominator: number of patients whose caregivers were given the care objectives and resuscitation status during or after admission or starting palliative care Denominator: total number of patients for whom this indicator was measured	Did your GP, the physician or other carers inform you of the patient's care objectives? ☐ Yes, ☐ No Did your GP, the physician or other carers inform you of the patient's resuscitation status? ☐ Yes, ☐ No	Indicator developed by the researchers together with an expert panel Measurement question developed by the researchers together with an expert panel

Table 2 Presentation of the minimal indicator set for palliative care in Belgium - continued

	Rater	Indicator description	Measurement question	Evidence of the indicator*
27	Ca	Nominator: number of patients for whom the prognosis, psychosocial symptoms, functional status, symptom burden and documentation about care wishes were entered in the file within 48 hours after admission or starting palliative care Denominator: total number of patients for whom this indicator was measured	Which of the following information was noted in the records within 48 hours after admission or starting palliative care? ☐ Patient's prognosis ☐ Patient's psychosocial symptoms ☐ Patient's functional status ☐ Patient's general symptom burden ☐ Documentation with regard to the patient's desired care and treatment	Indicator from Twaddle (2007): 'entering in file the prognosis, psychosocial symptoms, functional status and symptom burden within 48 hours after admission' Measurement question developed by the researchers together with an expert panel
		8. Care for family		
28	Fc	Nominator: number of family carers who indicated that the caregivers regularly talked to them about what it meant to them to care for their ill next of kin Denominator: total number of family carers who cared for their ill next of kin	Did the carers talk to you about what it meant to you to care for your sick relative? ☐ Yes, regularly ☐ Yes, once ☐ No	Modified indicator from Munday (2007: 'identifying and meeting the needs of informal carers, before the patient's death' Measurement question from Claessen (2009)
29	Fc	Nominator: number of family carers who indicated that the caregivers regularly asked how they were feeling Denominator: total number of family carers for whom this indicator was measured	Did the carers ask how you were feeling? ☐ Yes, regularly ☐ Yes, a few times ☐ No	Modified indicator from Claessen (2009): 'Extent to which, according to the direct relatives, attention was paid to their own psychosocial and spiritual well-being' Measurement question from Claessen (2009)

Table 2 Presentation of the minimal indicator set for palliative care in Belgium - continued

	Rater	Indicator description	Measurement question	Evidence of the indicator*
30	Fc	Nominator: number of family carers who felt they had adequate support after the patient's death (inclusive evaluation meeting) and were informed of the possibilities of after-care. Denominator: total number of family carers for whom this indicator was measured	Did you feel supported by the carers immediately after the death of your relative? ☐ Yes, ☐ No ☐ Not applicable. Was there a farewell- or staff appraisal interview that looked back on the care and treatment that was provided? ☐ Yes, ☐ No Were the possibilities of after-care pointed out to you after the death of your relative? ☐ Yes, ☐ No	Indicators from Claessen (2009): 'Extent to which direct relatives felt supported by the caregivers immediately after the patient's death', 'Extent to which direct relatives were informed about the possibilities of aftercare' and 'Extent to which a final conversation or discussion was held to evaluate the care and the treatment' Measurement questions of Claessen (2009)
31	Fc	Nominator: number of family carers who were given as much assistance as necessary with the care process Denominator: total number of family carers who needed assistance with the care process	Did you feel that the carers gave you all the help and support you needed to care for your relative? ☐ Yes, I received all the help I needed ☐ Yes, I received help but not enough ☐ No, although I tried to get more help ☐ No, but I did not ask for more help either ☐ I did not need any help	Indicator from Peruselli (1997): 'Satisfaction with family about assistance of caregivers in the care process for the patient' Measurement question from the VOICES questionnaire

* Source of the quality indicator and measurement questions that was used during the development trajectory: the indicators were either based on existing international indicators or developed by the researchers in cooperation with an expert panel when international indicators were lacking for that theme within palliative care; the measurement questions were either based on existing questionnaires or developed by the researchers in cooperation with an expert panel when specific questions retrieving the necessary information to calculate the indicators were lacking.

Quality indicators per respondent type

Patients. Only three indicators were selected immediately so five out of six needed to be selected during the discussion (table 3). Because of the overlap between indicator number 7 ‘Percentage of patients who indicated that the professional caregivers were most of the time or always attentive to their personal situation and needs’ and number 8 ‘Percentage of patients who indicated that the professional caregivers regularly assessed how they were feeling’, the experts decided to discard number 7 and include the other in the minimal set.

Table 3 Scores and decision per round of the indicators included in the questionnaire for patients

	Indicator title	Score R1		Decision R1	Decision R2
		Median score	Most prior		
1	Percentage of patients with a score of 3 or less on a scale of 0 to 10 (average over 3 days) for pain	6*	4	Discard	
2	Percentage of patients who were most of the time or always treated for pain	7*	4	Discard	
3	Percentage of patients who, after treatment, experienced significant improvement in pain	9	6	Select	Minimal set
4	Percentage of patients with a score of 3 or less on a scale of 0 to 10 (average over 3 days) for anxiety	7*	2	Discard	
5	Percentage of patients who were most of the time or always guided for anxiety	6*	4	Discard	
6	Percentage of patients who, after treatment, experienced significant improvement in anxiety	7*	5	Discard	
7	Percentage of patients who indicated that the caregivers were most of the time or always attentive to their personal situation and needs	8	4	Discuss	Discard
8	Percentage of patients who indicated that the caregivers regularly assessed how they were feeling	8	5	Discuss	Minimal set
9	Percentage of patients who were most of the times or always offered counselling when they were not feeling well or feeling less well	8	3	Discard	
10	Percentage of patients with a score of 5 or more on a scale of 0 to 10 for psychological wellbeing	6*	4	Discard	
11	Percentage of patients who indicated that the caregivers regularly talked to them about spirituality and religion in an understanding way	7*	2	Discard	

Table 3 Scores and decision per round of the indicators included in the questionnaire for patients - continued

	Indicator title	**Score R1**		**Decision R1**	**Decision R2**
		Median score	**Most prior**		
12	Percentage of patients with a score of 5 or more on a scale of 0 to 10 for spiritual well-being	6*	2	Discard	
13	Percentage of patients with a score of 5 or more on a scale of 0 to 10 for social well-being	6*	0	Discard	
14	Percentage of patients with a score of 5 or more on a scale of 0 to 10 for quality of life	8	8	Select	Minimal set
15	Percentage of patients who indicated that they could most of the time or always be alone and talk to someone undisturbed if wanted	7*	2	Discard	
16	Percentage of patients who indicated that the caregivers most of the times or always respected their personal wishes and that they could most of the time or always plan their day and decide about the care provided	9	8	Select	Minimal set
17	Percentage of patients who indicated that most or all of their caregivers respected their philosophy of life	7*	2	Discard	
18	Percentage of patients who indicated that a priest or spiritual counsellor was available	5*	0	Discard	
19	Percentage of patients who received the right amount of information about their diagnosis	8	6	Discuss	Minimal set
20	Percentage of patients who received the right amount of information about their prognosis	8	3	Discard	
21	Percentage of patients who received the right amount of information about the course of the disease	8	5	Discuss	Minimal set

Table 3 Scores and decision per round of the indicators included in the questionnaire for patients - continued

	Indicator title	**Score R1**		**Decision R1**	**Decision R2**
		Median score	**Most prior**		
22	Percentage of patients who received the right amount of information on the advantages and disadvantages of treatments	8	2	Discard	
23	Percentage of patients who received the right amount of information on palliative care options	8	5	Discuss	Minimal set
24	Percentage of patients who indicated that they most of the time or always received clear and comprehensible and never or sometimes contradictory information	8	4	Discuss	Minimal set
25	Percentage of patients who indicated that they discussed their wishes about care objectives with a physician	8	3	Discard	
26	Percentage of patients who are not receiving treatments they do not want	8	3	Discard	
27	Percentage of patients who are not receiving drugs they do not want	6*	0	Discard	
28	Percentage of patients who were most of the time or always able to have some privacy with their family carers if wanted	6	2	Discard	
29	Percentage of patients who believed that their caregivers were sufficiently informed of their medical care history to be able to provide the best possible care	6*	0	Discard	
30	Percentage of patients who most of the time or always felt they were given continuous care by their various caregivers	8	1	Discard	
31	Percentage of patients who mostly or entirely knew who to talk to about their care	7	2	Discard	

R1 = round 1/ home assignment R2 = round 2 / discussion meeting
Median score: on a scale from 1 to 9 Most prior: number of times found most prior by the experts
* The experts did not reach consensus on these indicators in the first scoring round (home assignment)

Professional caregivers. Experts still needed to select four out of seven indicators during the meeting (table 4). They decided to retain indicator number 8 'Percentage of patients who were asked how they felt about end of life decisions and euthanasia'. Furthermore they choose number 16 'Percentage of patients whose caregivers were given the care objectives and resuscitation status during or after admission or starting palliative care', one of the three indicators on transfers. Lastly, they selected indicators number 9 and 10 on communication and care planning.

Table 4 Scores en decisions per round of the indicators included in the caregivers questionnaire

	Indicator title	**Score R1**		**Decision R1**	**Decision R2**
		Median Score	**Most prior**		
1	Percentage of patients who were subjected to a general symptom assessment on a validated scale	8	7	Select	Minimal set
2	Percentage of patients who were subjected to a pain assessment, with or without pain scale	8	9	Select	Minimal set
3	Percentage of patients who were subjected to a delirium assessment, with or without delirium scale	7	4	Discard	
4	Percentage of patients treated for delirium	6	2	Discard	
5	Percentage of patients for whom the delirium improved substantially or completely after the treatment	6	1	Discard	
6	Percentage of patients whose shortness of breath was relieved within 48 hours after admission or starting palliative care†	8	7	Select	Minimal set
7	Percentage of patients who were subjected to an anxiety assessment, with or without anxiety scale	8	6	Discuss	Discard
8	Percentage of patients who were asked how they felt about end of life decisions and euthanasia	8*	8	Discuss	Minimal set
9	Percentage of patients about whom a conversation about their care preferences took place between the caregivers and family carers in the first week after admission or start of palliative care	8	6	Discuss	Minimal set
10	Percentage of patients about whom multidisciplinary consultations took place at least once a week about their care objectives	8	5	Discuss	Minimal set

Table 4 Scores en decisions per round of the indicators included in the caregivers questionnaire - continued

	Indicator title	**Score R1**		**Decision R1**	**Decision R2**
		Median Score	**Most prior**		
11	Percentage of patients whose family physician was regularly or always involved in these multidisciplinary consultations	6	4	Discard	
12	Percentage of patients whose wishes on resuscitation (DNR- code) are known to the caregivers	7*	6	Discard	
13	Percentage of patients whose family physician, home nurse and physiotherapist (when available) were involved in the care	7	4	Discard	
14	Percentage of patients whose caregivers were given information about care and treatment prior to admission or starting palliative care	8	4	Discuss	Discard
15	Percentage of patients whose caregivers were given a summary of the patient's medical records during the admission or after starting palliative care	8	5	Discuss	Discard
16	Percentage of patients whose caregivers were given the care objectives and resuscitation status during or after admission or starting palliative care	8	5	Discuss	Minimal set
17	Percentage of patients for whom the prognosis, psychosocial symptoms, functional status, symptom burden and documentation about care wishes were entered in the file within 48 hours after admission or starting palliative care	8	7	Select	Minimal set

R1 = round 1/ home assignment R2 = round 2 / discussion meeting
Median score: on a scale from 1 to 9 Most prior: number of times found most prior by the experts
* The experts did not reach consensus on these indicators in the first scoring round (home assignment)

Family carers. Five indicators were selected and seven still needed to be discussed after the home assignment (table 5). The experts selected indicator number 19 on quality of death and number 21 on after-care. The last indicator number 23 'Percentage of family carers who were given as much assistance as necessary with the care process' was retained as it was seen as covering a wide range of aspects.

Table 5 Scores and decision per round of the indicators included in the questionnaire for family carers

	Indicator title	Scores R1		Decision R1	Decision R2
		Median score	Most prior		
1	Percentage of patients for whom the delirium improved sufficiently after the treatment	7	0	Discard	
2	Percentage of family carers who indicated that caregivers were most of the time or always attentive to their anxiety and despondency	8	2	Discard	
3	Percentage of family carers who indicated that the caregivers regularly talked to them about what it was meant to them to care for their ill next of kin	8	7	Select	Minimal set
4	Percentage of family carers who indicated that the caregivers regularly asked how they were feeling	8	10	Select	Minimal set
5	Percentage of family carers who were most of the time or always offered counselling when they were not feeling well or feeling less well	8	3	Discard	
6	Percentage of family carers who indicated that the caregivers regularly talked to them about spirituality and religion in an understanding way	6	0	Discard	
7	Percentage of family carers who indicated that most or all of the caregivers respected their philosophy of life	7	1	Discard	
8	Percentage of patients who got a positive response to (all) their request(s) for a treatment or an end-of-life decision	9	11	Select	Minimal set
9	Percentage of patients who received the right amount of information about the treatment or end-of-life decision they requested	8	3	Discard	
10	Percentage of patients who were involved in the final treatment or end-of-life decision (after a request of the patient)	8	2	Discard	

Table 5 Scores and decision per round of the indicators included in the questionnaire for family carers - continued

	Indicator title	**Scores R1**		**Decision R1**	**Decision R2**
		Median score	**Most prior**		
11	Percentage of patients (or family carers in case the patient lacked capacity) who were sufficiently informed when a treatment or end-of-life decision was taken	8	4	Discuss	Discard
12	Percentage of patients (or family carers where the patient lacked capacity) who were involved in the treatment or end-of-life decision (without a request of the patient)	8	3	Discard	
13	Percentage of family carers who received sufficient information about palliative lump sum and palliative leave	8	2	Discard	
14	Percentage of family carers who received the right amount of information about the patient's condition and treatments	8	9	Select	Minimal set
15	Percentage of family carers who received the right amount of information about the patient's approaching death	9	7	Select	Minimal set
16	Percentage of family carers who received clear and comprehensible and non-contradictory information about the patient’s approaching death	8	4	Discuss	Discard
17	Percentage of patients for whom starting or terminating administration of artificial fluids and/or nutrition was discussed with family carers	7*	4	Discard	
18	Percentage of patients whose authorized representative was involved when the patient lost capacity	8	5	Discuss	Discard
19	Percentage of patients who scored 5 or more on a scale of 0 – 10 for the quality of death	8	5	Discuss	Minimal set
20	Percentage of family carers who were most of the time or always able to have some privacy with the patient if wanted	7*	0	Discard	

Table 5 Scores and decision per round of the indicators included in the questionnaire for family carers - continued

	Indicator title	**Scores R1**		**Decision R1**	**Decision R2**
		Median score	**Most prior**		
21	Percentage of family carers who felt they had adequate support after the patient's death (inclusive evaluation meeting) and were informed of the possibilities of after-care.	8	5	Discuss	Minimal set
22	Percentage of family carers who were given as much assistance and training as necessary for practical issues and had someone available for help with these issues	8	6	Discuss	Discard
23	Percentage of family carers who were given as much assistance as necessary with the care process	8	4	Discuss	Minimal set

R1 = round 1/ home assignment R2 = round 2 / discussion meeting
Median score: on a scale from 1 to 9 Most prior: number of times found most prior by the experts
* The experts did not reach consensus on these indicators in the first scoring round (home assignment)

Physicians. As the physicians' questionnaire originally included only nine indicators, experts were not asked to prioritise the eight most important in this list. Based on the median scores only, seven indicators were selected for the minimal set. The experts decided not to add any more to the minimal set as there was no agreement on the validity of the remaining two indicators (table 6).

Table 6 Scores and decisions per round for the indicators included in the questionnaire for physicians

	Indicator title	**Scores R1** **Median score**	**Decision R1**	**Decision R2**
1	Percentage of patients whose symptom burden was mostly or completely under control in the final week of life	9	Select	Minimal set
2	Percentage of patients with whom the physician discussed the care objectives	9	Select	Minimal set
3	Percentage of patients who were not started on artificial fluids and/or nutrition in the last month before death	7*	Discuss	Discard
4	Percentage of patients whose palliative care started at least 2 weeks before death	8	Select	Minimal set
5	Percentage of patients who were not started on a new course of chemotherapy after admission or start of palliative care	7*	Discuss	Discard
6	Percentage of patients admitted more than once to the emergency room since admission or start of palliative care	8	Select	Minimal set
7	Percentage of patients admitted to the intensive care unit since admission or start of palliative care	7	Select	Minimal set
8	Percentage of patients who scored 5 or more on a scale of 0 – 10 for the quality of death (according to family carers and physicians)	9	Select	Minimal set
9	Percentage of patients who were in touch with their family physician on a weekly basis in the last 3 months before death (personally or by telephone)	7	Select	Minimal set

R1 = round 1/ home assignment R2 = round 2 / discussion meeting
Median score: on a scale from 1 to 9 Most prior: number of times found most prior by the experts
* The experts did not reach consensus on these indicators in the first scoring round (home assignment)

Discussion

A two-round modified RAND/UCLA panel resulted in a minimal indicator set of 31 indicators for palliative care in Belgium. A panel of thirteen experts scored the previously developed and tested quality indicators for priority to be included in the minimal set. After this home assignment, a meeting took place where the experts discussed the indicators on which they had not reached consensus. The minimal set eventually selected is both limited and comprehensive at the same time, making it suitable for quick and efficient assessment of quality of care provided by mobile home care teams, palliative care units and palliative support teams in hospitals.

Our study has several strengths. To select the minimal indicator set we used a standardized method, ie the RAND method consisting of two rounds: a homework assignment and a panel discussion. The panel consisted of caregivers from different disciplines (ie physicians, psychologists and nurses from home and hospital settings) together with two experts representing the perspective of patients and their families (27). Some limitations have to be acknowledged. Most panel members scored all indicators high for priority. As we anticipated this problem we also asked the individual experts to pick the eight most important indicators in order to differentiate more between the indicators. A possible solution for the high scoring propensity can be to define every point on the scale very precisely and to provide examples of how to score the indicators for priority. An additional limitation is that two experts who participated in the home assignment did not attend the expert meeting as a result of their uncertain working schedules. An analysis of their scoring results indicates that their absence likely would not have influenced the ultimate result as their scores in the homework assignment were similar to those of other panel members.

At the end of the panel meeting, the minimal set consisted of 31 indicators chosen from the 80 previously developed and tested, spread over eight important domains. Although we informed the experts during the discussion about underrepresented domains in their provisional selection, not all domains are equally represented in the minimal set. This may be because of the varying importance the different PC teams attach to the domains in their care. Nevertheless, because we strived for comprehensiveness from the start of the development process, the domains seen as most important in the literature as well as in practice are well represented in the final minimal set.

The current format of a minimal set and optional modules gives users the chance to measure the quality of the care they are delivering with the minimal set in a quick and efficient but still comprehensive manner first and then to use one or more of the optional modules together with the minimal set to investigate a specific domain within palliative care in greater detail. The choice of measuring an optional module might be the result of a quality problem arising in a previous measurement or of a greater interest in the team in that specific domain. That each of the indicators is measured through one respondent type only (ie the one through which the literature or the experts deemed the indicator to be measured most validly) allows for comprehensive quality evaluation with the different questionnaires still limited in length.

Services can measure the indicators in the minimal set by making a cross-sectional selection of all patients enrolled in the palliative care service and still alive on that specific day and at the same time all patients enrolled in the service but who died in the previous four weeks to four months. For these patients the five corresponding questionnaires are distributed. This whole procedure requires two days of work from the person responsible. Anonymized responses are processed by an independent research team that calculates the quality indicator scores and feeds them back to the service in the form of a report. The care team members should then plan to meet to interpret the scores, distil working points and set up an action plan to improve quality of care. In principle, services need to repeat the measurement and evaluation procedure every six months.

In the future, all palliative care services will be invited to work voluntarily with the minimal quality indicator set and optional thematic modules in order to monitor their practice. By avoiding obligatory use of the indicators, caregivers will apply the quality information in a more well-considered manner. The use and feasibility of the minimal set and the indicators would need to be further evaluated and validated in the future (28). The minimal set can also be used as a basis for an international minimal set for palliative care. The use of such an international minimal set would then create more standardization of quality evaluation across palliative care services across different countries.

Conclusion

In selecting a minimal comprehensive set of quality indicators we have provided PC services with an indicator tool for quick and efficient assessment of the quality of the care they deliver in Belgium. Systematic measurement (every six months) with these indicators can generally identify the aspects of care that are going well and those that need improvement, hence serving as a barometer for the PC delivered by the specific service. Depending on the priorities different PC services set, action can be taken by the team to improve their care. Furthermore, the indicators can be used as a benchmarking tool at national and international level on the condition that case mix adjusters are identified and that policy makers implement the use of quality indicators as part of an improvement strategy for PC.

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PART IV

Towards an implementable quality indicator set for palliative care services in Flanders

Chapter 6

How to implement quality indicators successfully in palliative care services: perceptions of team members about facilitators and barriers to implementation

Kathleen Leemans, Lieve Van den Block, Robert Vander Stichele, Anneke L. Francke, Luc Deliens, Joachim Cohen

Submitted

Abstract

Purpose: There is an increasing demand for the use of quality indicators in palliative care. With previous research about implementation in this field lacking, we aimed to evaluate the barriers to and facilitators of implementation.

Methods: Three focus group interviews were organized with 21 caregivers from 18 different specialized palliative care services in Belgium. Four had already worked with the indicators during a pilot study. The focus group discussions were transcribed verbatim and analyzed using the thematic framework approach.

Results: The caregivers anticipated that a positive attitude by the team towards quality improvement, the presence of a good leader and the possible link between quality indicators and reimbursement might facilitate the implementation of quality indicators in specialized palliative care services. Other facilitators concerned the presence of a need to demonstrate quality of care, to perform improvement actions and to learn from other caregivers and services in the field. A negative attitude by caregivers towards quality measurement and a lack of skills, time and staff were mentioned as barriers to successful implementation.

Conclusion: Palliative caregivers anticipate a number of opportunities and problems when implementing quality indicators. These relate to the attitudes of the team regarding quality measurement, the attitudes, knowledge and skills of the individual caregivers within the team and the organizational context and the economic and political context. Training in the advantages of quality indicators and how to use them is indispensable, as are structural changes in the policy concerning palliative care, in order to progress towards systematic quality monitoring.

Background

Quality indicators are of great importance in the field of palliative care as they can provide information to caregivers on areas that require improvement and enhance transparency for patients and their families (1-6). Administrators and policy makers can use the information they provide to make quality improvements within care services (internal aim) and for comparisons between various care services (external aim) (7-9). Quality indicators are defined as measurable aspects of care addressing a specific quality issue or a related outcome (10-13). Hitherto, efforts to develop quality indicators for end-of-life care have mainly focused on characteristics of end-of-life care for cancer patients using administrative data (14-17) or are focused on outcome measures rather than on producing well-defined quality indicators (7;8;18). Only a few quality indicator sets have been developed specifically to monitor the quality of palliative care and they tend not to focus on all the various domains that make up palliative care (19;20). In Belgium we have developed a comprehensive quality indicator set which has been tested and judged as feasible and valid (21;22). It takes into account the perspectives of patients, family carers, professional caregivers and policy makers. The quality indicator set is meant for use in specialized palliative care services ie palliative care units, palliative support teams in hospitals and multidisciplinary palliative home care teams.

In order to be used systematically on a wide scale to monitor and subsequently improve the quality of palliative care, the quality indicators firstly need to be implemented successfully within palliative care services. Such implementation process requires extra attention and good preparation it will not follow automatically from development and dissemination (23;24). Grol et al. have suggested a five-step plan for successful implementation of an innovation in health care (25). After an innovation is developed (step 1), barriers and facilitators need to be identified (step 2) in order to develop implementation strategies (step 3) and an implementation plan (step 4) that can be used and evaluated in practice (step 5).
Insight into barriers to and facilitators of implementation of QIs - step 2 - provides the basis to ensure that implementation strategies are being adapted to specific situations, innovations and target groups (26). Given the increasing demand for the use of quality indicators in palliative care services across different countries, the difficulties inherent in the implementation of quality indicators, and the lack of research about barriers and facilitators of implementation in palliative care services, a study on how to implement quality indicators successfully in palliative care services was needed.

Although two previous studies (27;28), one concerning dementia care settings and one concerning intensive care units, have provided useful information about possible barriers and facilitators for quality indicator implementation (27;28) they did not specifically look at the context of specialist palliative care and it remains unclear whether their findings can be generalized to this context. Palliative care has its own unique and peculiar issues and organization (29-32). Hence this study aims to identify possible conditions that facilitate or impede implementation of quality indicators for specialized palliative care services, from the professional palliative caregiver’s perspective, across the three types of palliative care services ie palliative care units, mobile palliative support teams in hospitals and multidisciplinary palliative home care teams.

Methods

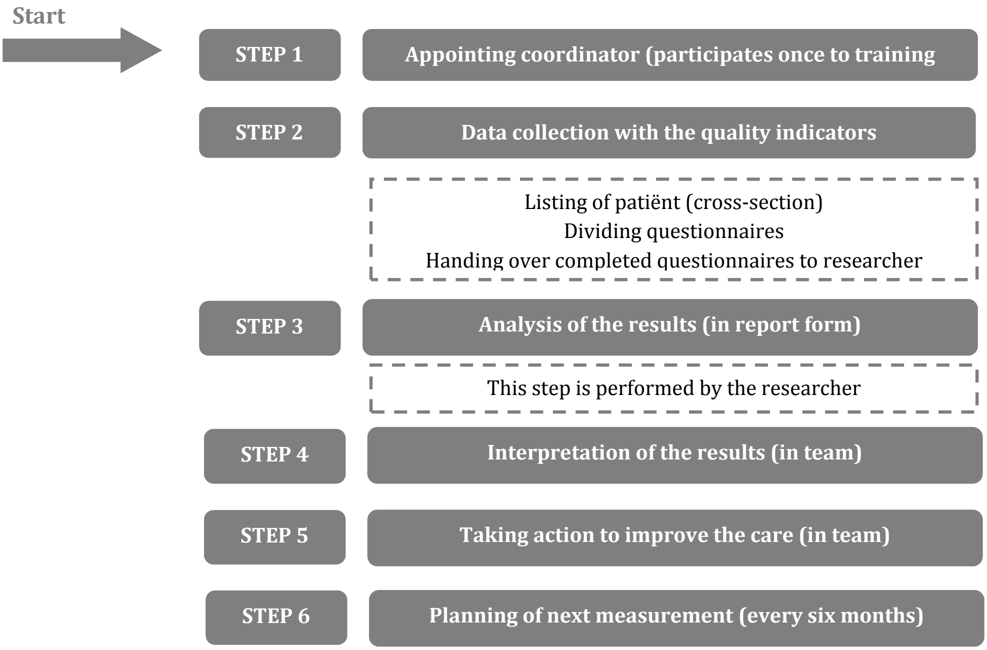
Design

Identification of barriers and facilitators as suggested by Grol et al. (25), is best addressed through a qualitative design as this allows for a more in-depth evaluation of underlying concerns and objections of relevant agents in the field of interest ie palliative care. Therefore focus group interviews were held with professional caregivers of palliative home and hospital care about the use of the developed quality indicator set in their service. The focus group approach allows for more insight into reasons for considering or not considering the use of the quality indicators for quality measurement within specialized palliative care services and even into possible solutions (33).

The quality indicator set (i.e. innovation aspect)

The quality indicator set was developed as a new innovation for palliative care services in Flanders (the Dutch-speaking part of Belgium), and consists of a comprehensive minimal set (31 indicators) and three optional thematic modules covering all domains of palliative care: physical aspects of care, psychosocial and spiritual/existential aspects of care, communication and care planning, coordination and continuity of care, type of care and circumstances surrounding death and structure of care. To measure the indicators, questionnaires are sent to patients, family carers and professional caregivers using a cross-sectional inclusion method. This implies that the palliative care services list two groups of patients on one day: 1) all patients that are being supported (ie all those enrolled and still alive) by the palliative care service on that specific day, 2) all patients enrolled in the service but who had died in the previous four weeks to four months. For the first group, a questionnaire is provided to the patient and the most important professional carer at that moment. For the second group, a questionnaire is sent to the most important family carer and professional carer (or the family physician for patients who died at home). The combination of both groups allows evaluation of both processes and outcomes of care and aspects of care in the days surrounding death (including aftercare for the family). After receiving all completed questionnaires from the respondents, the anonymized responses are sent to an independent research team which calculates the quality indicator scores and feeds them back to the service in the form of a report. The team members then, in principal, plan a meeting to interpret the scores, distil working points for the service and set up an action plan to improve quality of care. This procedure needs to be repeated every six months within one service to be able to measure the effects of improvement actions. Figure 1 present a schematic overview of the procedure; the whole procedure is described elaborately elsewhere (21;22).

Figure 1: schematic representation of how to measure the quality indicators for palliative care



Participants in the focus groups

Participants were purposefully recruited to participate in a focus group interview about the implementation of quality indicators within their specialized palliative care service. We wanted physicians and nurses as well as psychologists to participate as all these types of caregivers might have different views on quality measurement because of their background, education and work experience. We deemed it important for the dynamics of the discussion that persons who already had experience with quality indicator measurement within their service (through our previous feasibility study, (22)) were represented in each focus group. Additionally, the three types of palliative care services needed to be represented. An invitation was spread through the network coordinators of the 15 different palliative care networks in Flanders. Additionally, an invitation was sent directly to all services that had participated in the previous feasibility study.

Procedures

Three focus group interviews were held, one for the palliative care units (PCUs), one for the palliative support teams in hospitals (PSTs) and one for the multidisciplinary palliative home care teams (MHTs). We made this choice because we anticipated that the different organization of each type of service might evoke different barriers and facilitators. Initially, for the MHTs, no physicians were found available after sending around the invitation, so extra recruitment was conducted by personal email and telephone. Each focus group interview was led by an experienced moderator using an interview guide to structure the discussion (table 1). The interview guide was developed and reviewed within a multidisciplinary research team of psychologists (KL, LVDB), sociologists (JC, LD), a physician (RVS) and a nurse (ALF). Before the start of each focus group interview, all participants received the full manual on how to use the quality indicator set in palliative care services for quality measurement (specific manuals were developed for each of the three types of palliative care services). They were asked to read through the manual in advance, especially the measurement procedure. Each discussion lasted for 90 minutes and was audiotaped, for which all participants gave consent. Both the meetings and transcriptions, which were transcribed verbatim, were in Dutch.

Table 1 Interview guide and accompanying prompts for discussion during the focus group interviews

Question	Prompt
1. Would you in the future consider working with quality indicators within your palliative care service?	What are your expectations about working with quality indicators?
2. How would you use the quality indicators, as presented in the manual, within the working of your palliative care service?	What might be problems? What might be solutions?
3. Do you consider it possible to independently use the quality indicators, as presented in the manual?	What might be problems? What might be solutions?

Analysis

We performed thematic analysis (34) on the three transcripts, supported by Nvivo software. The thematic framework approach used consisted of five interconnected stages: familiarization, identifying a thematic framework, indexing (coding), charting and interpretation. The first author (KL) performed thematic coding using the existing framework of various levels of barriers and facilitators developed by Grol et al. (26). This model defines six levels of the healthcare system to examine barriers and facilitators: level of innovation (in this study the quality indicator set for palliative care services), level of individual caregiver, level of patient (in this study replaced by respondent to the questionnaire because of the nature of the innovation), level of organizational context, level of social context and level of economic and political context. Based on this analysis a tentative framework was identified dividing the six existing healthcare levels into subthemes that arose during coding. The tentative framework and one of the three transcripts were then presented to a second researcher (JC). Both researchers discussed the differences and reached consensus on the final thematic framework, which was then applied to all interview transcripts. During the coding and charting, the researchers took into account the possibility of identifying new levels of healthcare not yet defined in the literature (but none were found).

Ethics

A signed informed consent was obtained from each participant before the start of the focus group interview. Anonymity was assured by removing participant information that could lead to identification from transcripts. Because of the descriptive nature of the study and the involvement of professional caregivers only, no ethics committee was involved nor required. No socio-demographic characteristics were acquired from the participants.

Results

In total 21 professional caregivers (n = 7, n = 9, n = 5) from18 different palliative care services (n = 7, n = 7, n = 4) participated in the three focus group interviews (table2). Four of the 21 caregivers had already worked with the quality indicators during our feasibility study (21). For the palliative care unit (PCU), the invited physician cancelled one hour before the start of the interview due to family circumstances. Despite the extra recruitment effort, no physician was found to participate in the multidisciplinary palliative home care teams (MHT). The caregivers identified conditions facilitating or impeding implementation at all levels mentioned in the framework by Grol et al. except for the social context (table 3). We took the liberty of renaming the levels in the framework where this better matched the meanings within this study.

Table 2 Overview of participants per specialism in the three focus group interviews

	Focus group interviews		
	PCU	**PST**	**MHT**
N° of teams involved	7	7	4
N° of caregivers per specialism			
Head nurse	4	3	1
Nurse	1	2	1
Physician	/	1	/
Psychologist	2	2	2
Other*	/	1	1
TOTAL	**7**	**9**	**5**
Experience with QIs			
Yes	1	2	1
no	6	7	4

PCU = palliative care unit, PST = palliative support team, MHT = multidisciplinary palliative home care team

* For the PSTs one quality coordinator joined the focus group interview; for the MHTs one coordinator of a palliative network participated

Table 3 Conditions facilitating or impeding the implementation of quality indicators in palliative care at different levels of the healthcare system and per type of care service

Condition facilitating (f) or impeding (i) implementation	Mentioned in focus group		
	PCU	PST	MHT
Attitudes of the team regarding quality measurement (ie level of the innovation)			
Presence of a need to demonstrate quality of care (f)	+	+	+
An identified need for evidence-based improvement trajectories (f)	+	+	+
Presence of a desire to exchange ideas with and learn from other palliative care services (f)	+	+	+
Attitudes, knowledge and skills within the team (ie level of the individual caregiver)			
Perceptions of quality indicators as an individual evaluation (i)			+
Lack of knowledge and skills to work with quality indicators (i)	+	+	
Attitude of quality measurement as something outside the responsibility of caregivers (i)	+	+	+
Cautiousness to 'harm' respondents to the questionnaires (ie level of the respondents)			
A tendency to protect vulnerable patients and families (i)		+	+
Cautiousness to influence the relationship with the family physician (i)			+
Structure and organization of care (ie level of organizational context)			
Lack of time and staff to perform quality measurement (i)	+	+	+
Instabilities in the team (i)	+		+
Presence of electronic patient records (f)	+	+	+
Presence of a good leader to guide the quality measurement (f)	+	+	+
Interest in quality management from the directors (f)	+	+	+
Level of economic and political context:			
Willingness to transfer results of quality measurement to the Government (f)	+		+
Reimbursement for using quality indicators (f)	+	+	+
Possibility to link quality indicators to hospital accreditation (f)	+	+	

PCU = palliative care unit, PST = palliative support team, MHT = multidisciplinary palliative home care team

Attitudes of the team regarding quality measurement (ie level of the innovation)

Presence of a need to demonstrate quality of care: Participants explained that the quality indicators would serve the need to prove their quality of care in an appropriate manner. The data they currently collect for administrators are mostly quantitative process figures and the caregivers felt that these do not adequately cover the relevant aspects of their care. The need to demonstrate their quality of care was identified as facilitating implementation as quality indicators can provide information on the quality of care.

> Often we observe certain things with patients, but if we ask for them we get different results [...] those results are very interesting to me. Those things we want to measure. Kind of like customer satisfaction. (Network coordinator, MHT)

An identified need for evidence-based improvement trajectories: Most caregivers explained that they were already setting improvement goals within their teams and taking action to reach them but they felt that collecting evidence was necessary to see any effective improvement. Because quality indicators can provide such evidence and can be embedded into improvement trajectories, this need was seen as facilitating implementation.

> Of course, then you could see a result, you measure it. And you could see the result of the action you took. Otherwise we did something but did we benefit from it? If you don't measure it, you won't know. Then it is a subjective feeling. (Head nurse 1, PCU)

Presence of a desire to exchange ideas with and learn from other palliative care services: Most **c**aregivers expressed a desire to exchange quality information with other teams and services in order to learn from each other. They said that they could use the quality indicators to reveal other teams' specialties.

> It is important to close the circle, to extract goals. Not just for yourself but to see if we are improving. And to position yourself towards others. What teams are good at, what we can learn from each other. (Network coordinator, MHT)

Moreover, caregivers expressed the desire for benchmarking the quality indicator scores, as it would provide them with important information on how they are performing compared with similar services in their region.

Attitudes, knowledge and skills within the team (ie. level of individual caregiver)

Perceptions of quality indicators as an individual evaluation: According to the caregivers, team members' incorrect perception of quality indicators as an individual instead of a team evaluation impedes implementation.

> It will provide positive points and working points. And if you need to improve these working points you have to be careful that you don't accuse individual caregivers. (Head nurse, MHT)

Lack of knowledge and skills to work with quality indicators: All caregivers agreed that they had insufficient skills and knowledge about how to measure and calculate the quality indicators. This was perceived as impeding their ability to start working with the quality indicators.

Respondents suggested that extensive training is provided on how to measure, interpret and use indicators for quality improvements.

Attitude of quality measurement as something outside the responsibility of caregivers: Most caregivers expected the other team members to be worried about the capacity of the team and the timing when proposing to start measuring the quality of their care. For them, this attitude would impede implementation.

> Does the team see the possibility in this stadium, considering the evolution in the team at the moment, to perform it? Not just for the work load but are they ready to do something with it? (Psychologist 1, MHT)

Furthermore some caregivers pointed out that they did not see themselves as capable of assessing quality measurement and improvement; most saw it as the task of management.

Anxiety about harming respondents to the questionnaires (ie. level of respondents)

A tendency to protect vulnerable patients and families was identified as a condition that would impede implementing quality indicators Some of the caregivers of the MHT and PST focus groups indicated that they had previously wanted to start measuring the quality of their care eg by systematically asking patients and their families questions but had not done so out of fear that it would disturb them and they based these concerns on certain experiences.

> You are in that area, with people experiencing major concerns. Family members experiencing concerns, patients approaching their death. How can you start measuring things? (head nurse 2, PST)

Anxiety about influencing the relationship with the family physician was named as a barrier, as a questionnaire needs to be sent to the family physician to collect quality information. Caregivers of the MHT were concerned about disturbing the relationship with the family physician, as they are the key figures for the patient in their care.

> The relationship with the family physician, you need to keep it good. That is important to the patients. Sometimes it can already be fragile. (psychologist 2,MHT)

Structures and organization of care (ie. level of organizational context)

Lack of time and staff to perform quality measurement: All caregivers interviewed worried about the workload and the time investment needed to implement the quality indicators. They mentioned that the actual lack of time and staff would impede the implementation of quality indicators.

> I think you will have to involve someone extra to do that. Because at that moment, you cannot perform patient care together with quality measurement. (nurse, PCU)

PST and PCU caregivers saw a possible solution in involving the management. If they could be convinced of the advantages to the team and the hospital, they might be willing to give extra support and resources to overcome this barrier.

*Instabilities within the tea*m: Some caregivers were concerned about absences of team members due to prolonged illness, relocations and other project involvements. As long as not every team member is available, they felt it would be impossible to commit to quality measurement.

> At the time a team experiences a lot of pressure, the quality of the care decreases. That is not the right time to perform a quality measurement, when you feel such a pressure. (head nurse 1, MHT)

Therefore the caregivers felt the need to plan such quality measurement well in advance to overcome potential hurdles.

Presence of electronic patient records: Most caregivers wanted to use their electronic patient records for the listing of patients as well as reporting the indicators. They explained that it could automatize the quality measurement, reduce the workload and hence facilitate implementation. However, not all palliative care services have access to well-functioning electronic patient files.

> Our electronic patient file is not working that properly so that we can retrieve data on patients easily. (nurse, PST)

Presence for a good leader to guide the quality measurement: All caregivers explained that in order to use quality information to set improvement goals within their service and tackle them, a strong coordinator is needed to overview all tasks, motivate the team members and facilitate the implementation.

> […] I don’t think you can separate it from the coordinator. You can delegate as coordinator, but you cannot, or even you may not let go. (head nurse 2, PCU)

Interest in quality management from the directors: Some caregivers indicated that their team or hospital had already been searching for ways to measure and improve the quality of their care. According to the caregivers, such interest in quality measurement facilitates the implementation of quality indicators.

> This year at our hospital, initiated by the directors, they wanted to find out how they could measure the quality on the different wards. So the question was raised of how we could do it in our team. (psychologist 2, PST)

Economic and political context

Willingness to transfer results of quality measurement to the government to show how they are performing facilitates implementation of quality indicators**.** All caregivers pointed out that the government is busy developing controlling systems throughout all areas of health care. They think it is important for the government to take into account the quality of care alongside more quantitative figures because everyone agrees that it is important to strive for high quality care.

> […] everyone is convinced that you have to try to provide good quality care. Then they have to measure that together with the quantitative figures. I don't mind. They will measure anyway. Because they have to hand out their money. (head nurse 1, PCU)

Reimbursement for using quality indicators: Caregivers stated that being reimbursed for participating into quality indicator measurement would facilitate successful implementation. They argued that because of the existing shortcoming of resources in palliative care, especially shortness of staff, such extra reimbursement is necessary to guarantee measuring the quality indicators on a systematic basis within the palliative care services.

Possibility to link quality indicators to hospital accreditation. Caregivers of the PST and PCU mentioned that their hospital management had recently engaged in achieving accreditation. They said that this engagement would facilitate the use of quality indicators in palliative care services, as the quality indicators could help them achieve the accreditation.

> I think it might be a strong point if you can convince your management that it can play a role in achieving accreditation. I think it can even determine which improvement actions to choose for. (Head nurse 1, PCU)

As many hospitals in Flanders have recently enrolled for accreditation, caregivers mentioned that it is the right time to implement the quality indicators in the field of palliative care.

Discussion

Team members of palliative care services anticipate a number of opportunities and problems related to the implementation of quality indicators. These relate to attitudes of the team regarding quality measurement, attitudes, knowledge and skills of the individual caregivers within the team, a cautiousness about harming the respondents to the questionnaires, the organizational context and the economic and political context. Similar problems and opportunities for quality indicators were found across the three types of specialized palliative care services involved in this study, although certain specific opportunities and problems emerged that were inherent in the specific functioning and organization of the services.

The findings of this qualitative study confirm many barriers and facilitators in the literature concerning implementation of quality measurement such as lack of time and skills, the need for good leadership and training, using electronic patient files and receiving reimbursement (27;28;35-37). All these factors except lack of skills were mentioned in all three focus groups in this study. Other facilitators that were mentioned and have not already been described in the literature concerned the need to demonstrate quality of care, to perform improvement actions and to learn from other services in the field.

Despite strong similarities across the three types of services, some differences were found. Most were linked to the specific organization of the services, for example the anxiety about harming the relationship with the family physician was present particularly in the multidisciplinary home care teams as they provide him or her with palliative care support. The possibility of linking quality indicators to hospital accreditation was a facilitating condition mentioned in both hospital-based services.

Therefore, in order to create the optimal environment for successful implementation, specific strategies need to be developed. Once implementation is started based on a well-considered implementation plan, process evaluation is needed to evaluate the quality of the implementation process and the effectiveness of the strategies and to identify additional barriers and facilitators (25). Throughout the whole implementation process involvement of stakeholders should be retained in order to evaluate critically the progression towards a systematic quality monitoring and improvement system (9;38).

Limitations

Several limitations of our study need to be acknowledged. First, we chose to identify barriers and facilitators only from the perspective of the professional caregivers. We did not involve other stakeholders such as patients, family members or administrators. However, caregivers are involved in the implementation and it is they who will collect the data for the quality indicators. Moreover the quality indicators and accompanying measurement procedures have already been validated with patients and family members as part of a feasibility study. A second limitation involves the fact that a palliative care physician was not present in the focus groups of the palliative care units and the multidisciplinary palliative home care teams. We did not consider this to be a major issue as our feasibility study taught us that it is mostly the nurses and head nurses rather than consulting physicians who would have a substantial role in the implementation process of the quality indicators.

Conclusion and implications

In this study palliative care professionals indicated that a positive attitude of the team towards quality improvement, the presence of electronic records and the presence of a good leader would facilitate the implementation of quality indicators in specialized palliative care services. On the other hand a negative attitude by some individual caregivers towards quality measurement could impede successful implementation. Furthermore shortage of caregivers' time and staff shortages might impede the use of quality indicators within the services. Nevertheless the possible link between quality indicators and funding was seen as an important facilitating condition. Several actors need to anticipate on these barriers and facilitators in order to successfully implement quality indicators in palliative care services. Managers and directors should address the attitudes of the palliative caregivers towards quality measurement. Caregivers should be trained in using the indicators. Policy makers and administrators should develop tailored strategies in collaboration with the research field in order to create an optimal environment for palliative caregivers to be involved in systematic quality monitoring and improvement. Once the implementation process has started the effectiveness of the implementation strategies needs to be further evaluated.

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Chapter 7

How can palliative care services proof that they are delivering good care? Monitoring the quality of palliative care using quality indicators

Joachim Cohen, Kathleen Leemans.

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Background

Quality of care for the dying patient was one of the underlying concerns that inspired the writings and philosophies of Kubler-Ross, Cicely Saunders and other pioneer thanatologists (1;2). Since the late 1960s the hospice and palliative care philosophies have slowly spread across various countries and in many developed countries the delivery of care for persons facing a terminal illness is now partly organized in specialized palliative care services, sometimes regulated and integrated within general health care, sometimes still organized in a dispersed and localized manner (3). In many countries different types of services have been put in place including palliative home care services, palliative hospital-based mobile teams, and separate palliative care units or free-standing hospices (3).

With the increasing availability of (specialized) palliative care services across developed countries and their improved integration within regular health care (as part of a mainstreaming process) it is also becoming increasingly pertinent to systematically demonstrate the quality of care they are delivering. Many services, in terms of their organization, have accountability towards umbrella organizations or other hierarchical levels and are forced to go along with a logics of rationing of resource use (ie the best possible quality with limited resource use), or of accreditation systems based on quality norms. But also palliative care services that do not have accountability towards external authorities are, in a context of increasing demands of efficacy, struggling with question such as "how can we demonstrate that we are delivering good quality palliative care?", "what aspects of our care need improvement?", and "how can we successfully achieve this?".

Palliative care is lagging palpably behind other domains of health care in terms of methods to systematically evaluate and demonstrate quality. Although many services are evaluating their quality in some way or another, they are often basing this evaluation on implicit assumptions about what patients and their families find important and on ad hoc evaluations, often based on dialogues with bereaved family members to discuss their experiences and specific concerns. It remains a challenge to measure quality of palliative care in a systematic and valid manner so that the results can be used to improve care where necessary. In this article we will argue that quality indicators, specifically designed for palliative care can address this challenge. We will first explain the purpose and requirements of good quality indicators and then illustrate their use within palliative care based on a recently developed indicator set in Belgium.

Quality indicators

Quality indicators are well defined and measurable aspects of care, generally expressed in a number or percentage, expressed at an aggregated level, often the level of care organizations (4) (Table 1).

Table 1: properties of a quality indicator that have to be defined

Property	**Description**	Example (from the minimal set in BE)
Title of the indicator	What the indicator is about	General symptom assessment with a validated scale
Reason of the indicator	The relation of the indicator to the quality of care	Every patient should be submitted to a general symptom assessment when he or she is admitted to palliative care
Nominator	Population of patients for whom the indicator is positive	number of patients who were subjected to a general symptom assessment with a validated scale
Denominator	Population of patients that is evaluated	total number of patients in the palliative care service for whom this indicator was measured
Exclusion (optional)	The population that needs to be excluded because of irrelevance.	None
Type of indicator	Structure, process or outcome indicator (see table 2)	Process
Registration method	Which instrument and which population	Question in the questionnaire for the professional caregivers: Have you or any other caregiver evaluated the patient's symptom burden since the admission or start of palliative care? ○ Yes, with a scale ○ Yes, without a scale ○ No
Threshold value (optional)	A standard of quality (norm) or benchmark	Not set yet due to the lack of previous evidence. Could for instance be based on a best practice example.

Difference between quality indicators and outcome measures

Both terms are often being used interchangeably and mistakenly. Outcome measures provide a way to evaluate patient- or family level status and responses to treatment. They evaluate "the change in a patient's current and future health status that can be attributed to preceding healthcare". It expresses quality at an individual level. Quality indicators express quality at an aggregated level, usually the level of a health care service, an institution, a region or a full country. Although outcome measures are often (and ideally) the basis of quality indicators, in themselves they do not yet have the necessary properties and collection and calculation specifications to serve as quality indicator (5). Moreover, some outcomes may be considered adequate as a quality indicator (ie as an aggregate measure indicating quality issues) but inadequate as an outcome measure (ie as a tool to evaluate quality of individual patient care).

Purposes of quality indicators

Quality indicators can provide useful information to several stakeholders (6):

- To patients and families as they can enhance transparency
- To caregivers about aspects of care that need improvement
- To administrators and policy makers to show how care providers are performing and what structural support is lacking for the desired outcomes
- To researchers as they allow comparing quality of care over time and between care services or regions

An additional possible purpose of quality indicators is that they can be used to measure the effect of care innovation interventions and programs.

Structure, process and outcome quality indicators

The most widespread classification of quality indicators distinguishes structure, process and outcome of care (table 2) (7). Although often only process and structure indicators are used because they can be reported based on medical charts or administrative databases (and hence are inexpensive and easy to measure), taking all types of quality indicators into account, has the major advantage that outcomes of care can be related to (and improved through changes in) processes of care which on their turn can be related to structures of care. Therefore in order to measure and improve the quality of care, all three kinds of quality indicators have to be taken into account for the best result.

Table 2: Structure, process and outcome of care: three types of quality indicators (7)

	Description	**Example of quality indicator from the Belgian QI set for palliative care**
Structure of care	The attributes of care services, ie material resources (eg facilities, equipment), human resources and organizational structure (eg medical staff organization)	Nominator: Number of services with an oral or writing 'care for carers' policy Denominator: total number of services for whom the indicator was measured
Process of care	What is actually done in providing and receiving care, ie patient's activities in seeking care as well as caregiver's activity in making a diagnosis, recommending or implementing treatment	Nominator: number of patients who were subjected to a pain assessment, with or without pain scale Denominator: total number of patients in the palliative care service for whom this indicator was measured
Outcome of care	The effects of care on the health status and quality of life of patients and their family	Nominator: number of family carers who received the right amount of information about the patient's approaching death Denominator: total number of family carers for whom this indicator was measured

Quality indicators for palliative care

Unlike many other health care services, palliative care does not only focus on patients but also on their families (8), addresses physical problems as well as psychological, social and existential issues resulting from a terminal illness, and includes bereavement support (9). Palliative care is comprehensive and holistic and this implies that to measure the 'quality of palliative care' a quality indicator set needs to reflect this comprehensive and holistic character. Developing good quality indicators for palliative care is, therefore, also substantially more challenging than for other health care services, where quality is usually measured by at most a handful of 'core indicators'.

Worldwide, a limited number of efforts have tried to address this challenge, although none of them seem to be fully comprehensive in the sense that they do not cover all relevant domains of palliative care, do not integrate patient, caregiver, and family perspectives, or do not measure structure, process and outcomes of care (10). To address this hiatus we initiated a rigorous development process to compose a comprehensive quality indicator set for specialized palliative care in Belgium, following five stages (11):

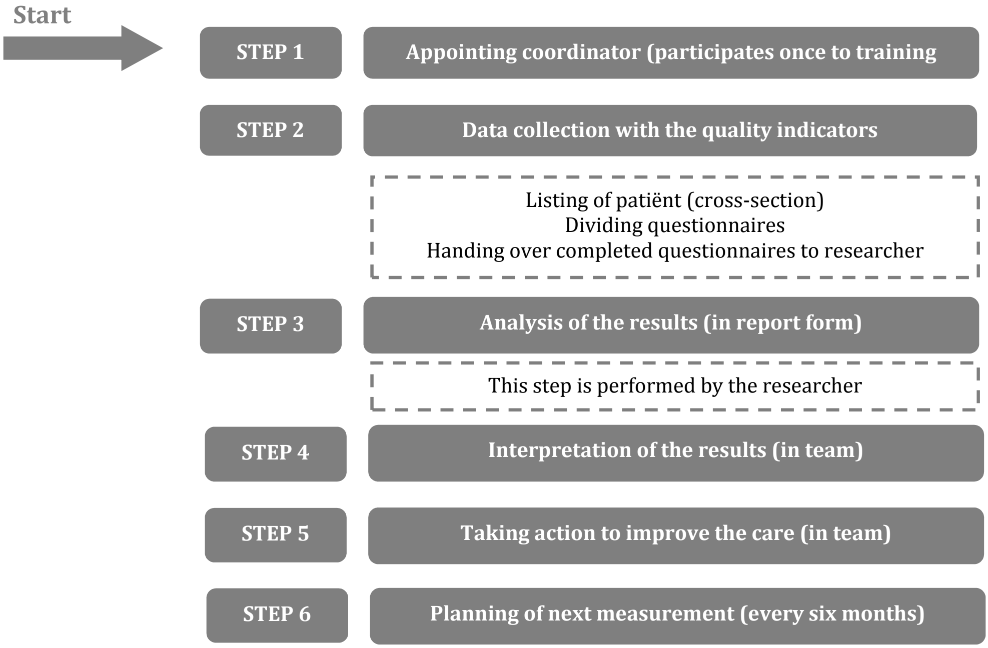
1. Systematic literature review to identify existing indicators for palliative care (12).
2. Identification of the important domains of palliative care and the priority themes and indicators of quality of palliative care using a robust consensus methodology taking into account perspectives of relevant stakeholders, ie patients, family carers, professional caregivers and policy makers (11). This resulted in a comprehensive set of quality indicators for palliative care.
3. Operationalization of the selected quality indicators into measurement instruments and methods.
4. A feasibility study of the quality indicators and measurement procedure in a number of palliative care services in Belgium. This phase indicated the indicators to be judged as clinically relevant and manageable by the palliative care providers, positively evaluated feasibility, usefulness, face validity and discriminative power of the indicators, and indicated a number of minor changes to be made to the measurement procedure and to certain indicators.
5. Selection of a 'minimal' set of 31 quality indicators, through expert consultations, to be implemented nationwide.

Measurement procedure of the quality indicators

The final quality indicator set exists of a comprehensive minimal set (31 indicators) and three optional thematic modules covering all domains in palliative care: physical aspects of care, psychosocial and spiritual aspects of care, communication and care planning, coordination and continuity of care, type of care and circumstances surrounding death and structure of care. We will here give a short description of the measurement procedure so as to illustrate how the set is to be used by (specialized) palliative care services (ie palliative care units, mobile palliative support teams in hospitals and the multidisciplinary palliative home care teams).

To measure the indicators, questionnaires are sent to patients, family carers and professional caregivers using a cross-sectional inclusion method. The cross-sectional inclusion measurement implies that the palliative care services list 2 groups of patients at one given day: 1) all patients that are enrolled in the palliative care service and still alive at that specific day, 2) all patients enrolled in the service but who died 4 weeks to 4 months ago. For the first group, a questionnaire is provided to the patient and the most important professional carer at that moment. For the second group, a questionnaire is sent to the most important family carer and the most involved caregiver. The combination of both groups allows evaluating both the processes and outcomes of care and the aspects of care in the days around death (including care and aftercare for the family). A maximum of two reminders are sent to the family physicians and professional caregivers that did not respond to the questionnaire within 21 days. After receiving back all completed questionnaires, anonymized responses are sent to an independent research team that calculates the quality indicator scores and feeds them back to the service in the form of a report. The care team members then, in principal, have a meeting to interpret the scores, distillate working points for the service and set up an action plan to improve quality of care. This procedure needs to be repeated every six months within one service to be able to measure the effects of improvement. Figure 1 present a schematic overview of the procedure; the whole procedure is elaborately described elsewhere (11).

Figure 1: schematic representation of measurement procedure of the quality indicators for palliative care



Conclusion and recommendations

Optimizing the quality of palliative care implies a valid and systematic measurement of the quality of that care. Quality indicators are the optimal tool to do so. In addition to the general requirements of quality indicators, good quality indicators for palliative care need to reflect the comprehensive and holistic character of palliative care. In developing and validating a minimal but still comprehensive set of quality indicators we have provided palliative care services with an indicator tool for quick and efficient assessment of the quality of care they deliver. Services can use these indicators as clinical indicators within their service to identify care aspects that need improvement. Depending on their priorities, action can be taken to improve their care, eg by offering training or specific tools to team members. In the longer run, as soon as the indicators have been widely implemented and risk adjusters identified, they can also be used as performance indicators beyond service level to benchmark and compare quality between different care services. The challenge for palliative care and for health care policy is to create the circumstances allowing an effective and successful implementation of the quality indicators into the standard functioning of the services. Although our set was developed for Belgium, palliative care services in other countries can use it to evaluate and improve their quality although quality priorities might be country-specific. However, irrespective of what indicator set is used, the systematic use of valid palliative care quality indicators will be a major step forward towards a quality evaluation and improvement process within palliative care.

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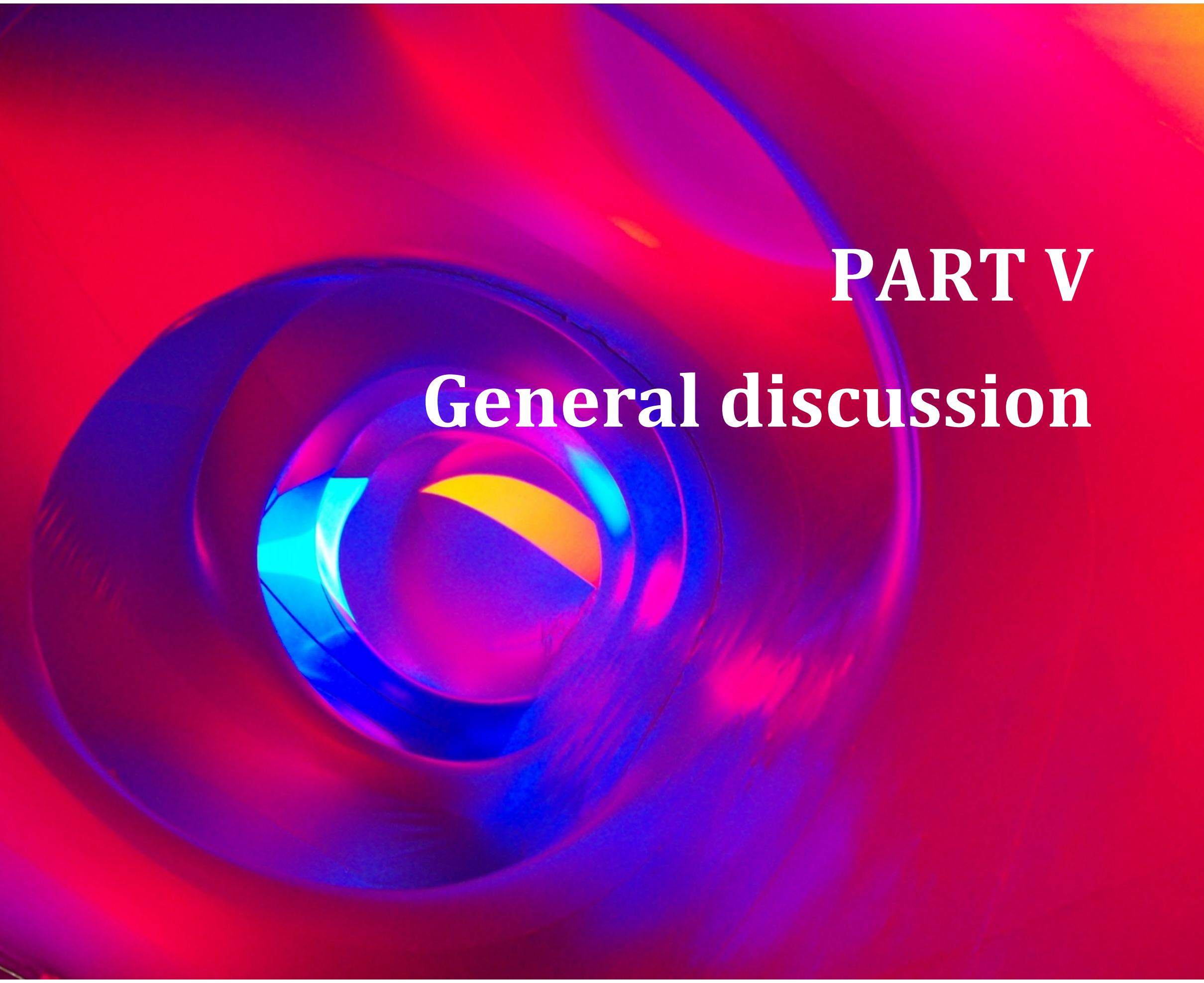


PART V

General discussion

Chapter 8

Main findings and general discussion

MAIN FINDINGS AND GENERAL DISCUSSION

This thesis presents the development trajectory of a quality indicator set for palliative care and an accompanying implementation strategy. Quality indicators can facilitate transparency and improvement in the care. They provide important information for patients, caregivers, policy makers as well as researchers. The Council of Europe as well as the World Health Organization (WHO) encourages the development of valid and reliable quality indicators in the field of palliative care. So far, no quality indicators were developed for Belgian palliative care services. This thesis contributes to the systematic monitoring and improvement of palliative care by presenting a rigorously developed, well defined and valid quality indicator set for palliative care services.

This discussion chapter first summarizes the main findings of this thesis and then discusses the findings in the light of the state-of-affairs in end-of-life care research and practice. It ends with a number of implications for practice, policy and future research.

Summary of main findings

In order to develop a comprehensive quality indicator set and accompanying implementation strategy for palliative care we followed a **3 step development trajectory**. Each step was discussed in a different part in this book:

- Part II: development of the indicator set (step 1),
- Part III: feasibility testing and fine-tuning of the indicator set (step 2)
- Part IV: preparing large-scale implementation of the indicator set (step 3)

Throughout these 3 steps, following research questions were addressed in this thesis:

Step 1: Development process

1. What international quality indicators already exist to measure the quality of palliative care? (chapter 2)
2. What method should be used to develop quality indicators that are suitable for measuring the quality of palliative care? (chapter 3)

Step 2: Feasibility testing and fine-tuning

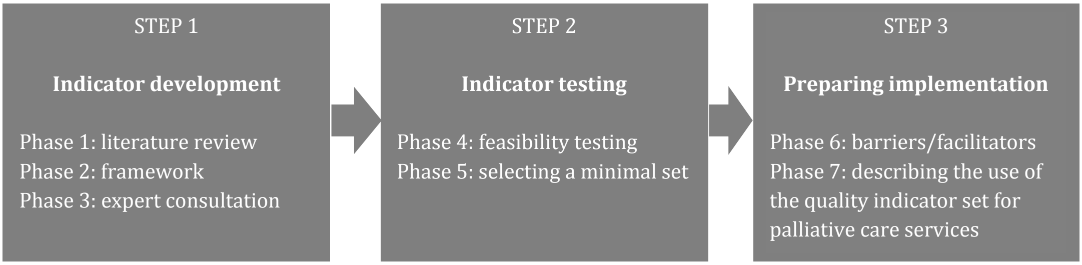
3. Are the quality indicators selected for palliative care in Flanders feasible, usable and valid? (chapter 4)
4. Which quality indicators need to be selected for a minimal set in order to measure quality of care in a quick and efficient manner? (chapter 5)

Step 3: Towards implementation

5. What are barriers and facilitators, from professional caregivers' perspective, when implementing quality indicators into the palliative care services in Flanders? (chapter 6)
6. How can palliative care services monitor the quality of their care using quality indicators? (Chapter 7)

Each research question can be seen as a seperate phase within the 3 step trajectory, as presented in figure 1. The main findings of the deveopment trajectory will be discussed per step and phase below.

Figure 1 Overview of the 3 step development trajectory for quality indicators



Development of a quality indicator set for palliative care (step 1)

In the first phase of the development trajectory we wanted to investigate which quality indicators already existed within the international field of palliative care before we could develop quality indicators for the palliative care services in Flanders, the Dutch speaking part of Belgium. Therefore we decided to conduct an update of a systematic literature review that was done by Pasman et al. in 2007, as described in chapter 2 of this thesis. Our systematic review was performed in 2009 and gave an overview of all published quality indicators for palliative care and identified any new developments from 2007 up to 2009 regarding the number and type of indicators developed and the methodology applied. This update was necessary because there had been increasing interest in quality measurement using quality indicators in the years before at international conferences, in policies and in the literature. Therefore it was likely that new sets of quality indicators had been developed and that some of the methodological characters in the previous review will have been explored in more detail. The literature search resulted in 435 hits in addition to the 650 hits found in the previous review. Thirteen new publications were selected (1-13) in addition to the 16 publications selected earlier (14-34), describing nine new sets in addition to the eight sets found in the previous review. All 17 sets of quality indicators contain in total 326 unique indicators. Most sets in the original review were developed in the U.S., whereas the nine new sets included some developed in The Netherlands, Japan and the U.K. In addition four of the new sets were found with a relatively broad focus. One set applies to all settings in which palliative care is provided for adult patients and was developed in the Netherlands (1;13), one set was developed for use in a variety of specialist care settings in Australia (8;12), and two sets focus on palliative care in several settings in the U.K. (10;11). The 17 sets together covered all domains of palliative care as defined by the U.S. National Consensus Project (35-37): 1) structure and process of care, 2) physical aspects of care, 3) psychological and psychiatric aspects of care, 4) social aspects of care, 5) spiritual, religious and existential aspects of care, 6) cultural aspects of care, 7) care for the imminently dying patient and 8) ethical and legal aspects of care. However, coverage is not equally distributed across the domains. The domains “Social Aspects of Care” and “Spiritual, Religious and Existential Aspects of Care” were underrepresented, although Pasman et al. (38) suggested that extra attention should be paid to the development of quality indicators in these latter domain. Of the 326 indicators, 199 referred to care processes and 117 to outcomes. Only 22 indicators for the structure of palliative care were found, with fourteen of the coming from one set (10). The extent to which methodological characteristics were described varied widely. Some indicator sets and their developmental 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. More consistent and detailed methodological descriptions are needed for further development of these indicators and improved measurement of palliative care.

Now that an overview was available of all existing indicators for palliative care, quality indicators, suitable for palliative care services in Flanders covering all important domains, could be selected, adapted or developed. With good examples of systematic and scientifically rigorous development trajectories for quality indicators for palliative care lacking in the literature, we intended to contribute to the establishment of a scientifically rigorous standardized and applicable method of measuring usable quality indicators. Chapter 3 describes the protocol we used for developing and validating a quality indicator set (step 1 and 2 in the trajectory) for palliative care for adults in Flanders, applicable in all settings providing palliative care. In order to develop and validate a comprehensive set of quality indicators to monitor the quality of palliative care in Flanders, four phases needed to be followed in the development process: 1) identification of existing quality indicators, 2) development of a framework for quality of palliative care, 3) indicator selection by expert consultations and 4) testing the draft quality indicator set in palliative practice. In the first phase, we conducted an update of a systematic literature review as described above. In the second phase, to achieve eventual comprehensiveness in the set of quality indicators, we conceived a conceptual framework based on publications focusing on the determination of high quality palliative care consisting of several domains (39-41): 1) physical, 2) psychological, social and existential, 3) information, communication, planning and decision making with patients, 4) with family and 5) with other carers, 6) type of care, 7) coordination and continuity, 8) support of friend or family carers and 9) structure of care. Within these nine domains, we distinguished several themes. Then the most relevant themes were selected by an expert panel representing all relevant actors in palliative care, including patient and family perspectives. In the third phase, the selected themes were then translated into quality indicators (i.e. with standardized specifications detailing the eligible population, data collection procedures, numerator and denominator), using the quality indicators found in the systematic literature review in the first phase. They were scored by a second multidisciplinary expert panel for usability and relevance, in keeping with the RAND/UCLA-method, combining evidence with consensus among stakeholders. This panel included professional carers and policymakers as well as patients and next-of-kin. This panel meeting led to a comprehensive quality indicator of 85 indicators divided over the 9 initial domains. In the fourth phase of the development and validation process, the draft set needed to be tested and evaluated in practice for usefulness and feasibility; the results of this fourth phase are described below. To encourage the acceptance and use of the indicators, stakeholders, including national palliative care organizations, were involved throughout the whole project.

Testing and fine-tuning the indicator set (step 2)

After development and before implementation of a comprehensive quality indicator set for palliative care, the indicators need to be tested and evaluated in practice, as presented in chapter 4 (phase 4). The indicators were tested in terms of face validity, feasibility, discriminative power and usefulness. Face validity can be defined as the extent to which an indicator is subjectively viewed as covering the concept it purports to evaluate (42;43). Feasibility mainly refers to the measurability of the quality indicators and the cost-benefit of the measurement procedure (42;43). Discriminative power looks at the capability of the indicator to discriminate between good and bad quality (42;43). Usefulness concerns the extent to which results can be applied by caregivers (42;43). The aim of the feasibility study was to test the developed quality indicators rigorously on a small scale in all types of palliative care services in Belgium by assessing their face validity, feasibility, discriminative power and usefulness and their measurement procedure in actual palliative care practice. Therefore the quality indicator set was used in nine palliative care services in Belgium: two multidisciplinary mobile palliative home care teams, two palliative care units, two multidisciplinary mobile palliative support teams in hospitals and three care homes for elderly. To evaluate the quality indicators and measurement procedure, we used a mixed method design including a quantitative cross-sectional application of the quality indicators and qualitative interviews with caregivers using the indicator set. To gather all data needed to calculate the quality indicators (i.e. by dividing the nominator and denominator) questionnaires were sent to the patients of the services, their caregivers, family carers and physicians. The response rate was 56% for patients, 97% for caregivers, 56% for family carers and 65% for physicians, indicating good feasibility of the measurement procedure. During the interviews caregivers found the indicator scores valid and none were extremely skewed, confirming their discriminative power. Still, 20 of the 80 indicators showed problems of feasibility and five of usefulness. One was discarded and the others were improved by changing either the formulation of the indicator or the questions used. Based on the results, minor adjustments were made to individual indicators, to the measurement tools and to the procedure used. At this point, the quality indicator set consisted of 84 indicators divided in three modules: 1) bio-psycho-social and spiritual aspects of care, 2) communication and care planning and 3) coordination of care and circumstances surrounding death.

During the qualitative interviews of the feasibility study, most caregivers expressed the need for a minimal but still comprehensive indicator set, i.e. covering the nine original domains, to monitor quality involving a limited workload for the team and short questionnaires for the patients, caregivers and family carers. Therefore in phase 5 we decided to trim the comprehensive set to a minimal indicator set for quicker and more efficient assessment while still covering all elements inherent to palliative care (chapter 5). To do so, a two round modified RAND/UCLA expert panel was conducted. The panel was composed of experts in the field of palliative care in Belgium. They were recruited from three areas: researchers in palliative care, palliative care providers and palliative care users. In total 13 experts participated: one researcher, four physicians, four nurses, two psychologists, one volunteer and one representative of a patient organization. In a home assignment the experts were asked to score 80 developed process and outcome indicators (excluding the four structure indicators) for 'priority' to be included in the minimal set on a scale from 1 (lowest priority) to 9 (highest priority). The second round consisted of a plenary meeting in which the minimal set was finalized. Thirty-nine of the 80 indicators were discarded while 19 were definitely selected after the home assignment and 22 were proposed for discussion during the meeting; twelve of these survived the discussion round. At the end of the discussion the minimal set for home and hospital palliative care in Belgium consisted of 31 indicators: five about physical aspects of care, three about the psycho-social-spiritual aspects, 11 about information, communication and care planning, five about type of care, three about continuity of care and four about care for family. The four structure indicators were added to minimal set to be measured by default as well. Hence the minimal set covered all the original quality domains. The 49 indicators that were not selected for the minimal set were kept into the topic-specific modules that are optionally available for more thorough assessment of specific aspects of care.

Towards implementation of the indicator set (step 3)

Although the indicator set was now ready to be used on a large scale in palliative practice in Belgium, it remained important that barriers and facilitators, and strategies for implementation were mapped before the set could be used for quality monitoring and improvement on a nationwide level (44-46). Furthermore it was deemed important to summarize briefly how palliative care services could use the minimal quality indicator set and optional modules to evaluate and improve the quality of their care.

Therefore in phase 6, possible conditions were identified that facilitate or impede implementation of quality indicators for palliative care, from professional palliative caregivers' perspective, across the three types of palliative care services: palliative care units, mobile palliative support teams in hospitals and multidisciplinary palliative home care teams (chapter 6). To do so, three focus group interviews were held; one for the palliative care units, one for the palliative support teams in hospitals and one for the multidisciplinary palliative home care teams. We made this choice because we anticipated that the different organization of each type of service might evoke different facilitating or impeding conditions. The study revealed that palliative care team members of the different types of palliative care services anticipate a number of opportunities but also problems related to the implementation of quality indicators for palliative care. These relate to attitudes of the team regarding quality measurement; attitudes, knowledge and skills of the individual caregivers within the team, a cautiousness to harm the respondents to the questionnaires, the organizational context; and the economic and political context. Similar problems and opportunities for quality indicators were found across the palliative care units, palliative support teams in hospitals and multidisciplinary palliative home care teams although certain specific opportunities and problems emerged that were inherent to the specific functioning and organization of the services. The conditions that we identified in this study can be used to develop service specific implementation strategies and an implementation plan. This will be further explained later in this discussion section (under implications for policy, practice and research).

Last, chapter 7 gives an overview of how quality indicators can be used to monitor quality of palliative care from the perspective of the palliative care services. Describing the use of the quality indicator set from a practical point of view is the last phase in this development trajectory, before implementation can start. In short, to measure the indicators, questionnaires are sent to patients, family carers and professional caregivers using a cross-sectional inclusion method. The cross-sectional inclusion measurement implies that the palliative care services list 2 groups of patients at one given day: 1) all patients that are enrolled in the palliative care service and still alive at that specific day, 2) all patients enrolled in the service but who died 4 weeks to 4 months ago. For the first group, a questionnaire is provided to the patient and the most important professional carer at that moment. For the second group, a questionnaire is sent to the most important family carer and the most involved caregiver. The combination of both groups allows evaluating both the processes and outcomes of care and the aspects of care in the days around death (including care and aftercare for the family). After receiving back all completed questionnaires, anonymized responses are sent to an independent research team that calculates the quality indicator scores and feeds them back to the service in the form of a report. The care team members then, in principal, have a meeting to interpret the scores, distillate working points for the service and set up an action plan to improve quality of care. In the longer run, as soon as the indicators have been widely implemented and risk adjusters identified, they can also be used as performance indicators beyond service level to benchmark and compare quality between different care services. The challenge for palliative care and for health care policy is to create the circumstances allowing an effective and successful implementation of the quality indicators into the standard functioning of the services. This will be elaborately discussed in the last part of this discussion (under implications for policy, practice and research).

A comprehensive quality indicator set for palliative care services

The ultimate result of this PhD trajectory is a valid and comprehensive indicator set of 84 indicators suitable for quality measurement and improvement by multidisciplinary palliative home care teams, palliative care units, multidisciplinary mobile palliative support teams in hospitals and palliative care reference nurses in care homes (box 1).

Box 1 Composition of the quality indicator set for palliative care services

To measure by default:
A minimal comprehensive set of process and outcome indicators covering different domains of palliative care (31 indicators)
Structure indicators (4 indicators)

To measure by choice:
Three optional thematic modules of process and outcome indicators:

1. Bio-psycho-social and spiritual aspects of care (23 indicators)
2. Communication and care planning (16 indicators)

The appendix compounds the 31 indicators of the minimal set and the four structure indicators, all with measurement questions in English (based on a forward-backward translation of the set in Dutch). The complete indicator set (in Dutch) is available upon request from the author of this book. Next in this chapter we will discuss the methodological strengths and limitations of the development trajectory that was followed during the PhD trajectory.

Methodological strengths and limitations

Methodological strengths

Palliative care differs from other health care areas as it claims to provide holistic care to patients and their families (39;47-53). In order to measure the quality of palliative care, the most suitable quality indicator set would be the one that succeeds in covering this multifaceted approach (48;49;51;54-60). To reach this necessary comprehensiveness, a rigorous development process should be followed. In the literature little is described about the methodological characteristics and development processes of existing indicators for palliative care. Our systematic literature review identified the need for better understanding and hence publication of methodological characteristics of indicator sets for palliative care, including an extensive description of the development process that was used. Our method comprised different phases of previous development processes (i.e. literature review, expert consultation, practical test) in combination with certain new elements: inclusion of patient and family perspective, structure, process and outcome indicators and the applicability to all patients in all palliative care services. Therefore we were able to present a scientific rigorous method that is appropriate to develop a set that meets the level of comprehensiveness required for palliative care. The method could serve as a standardized method for developing quality indicators for palliative care in other countries (figure 2).

Figure 2 Standardized method for comprehensive quality indicator development in palliative care

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

Several phases in the rigorous development process added to the comprehensiveness of our indicator set. The set was composed starting from a comprehensive framework that reflecting all domains that are important to measure the quality of palliative care. Next to a literature search that revealed nine important domains in quality palliative care, we consulted an expert panel to choose subthemes for each of the nine domains that needed to be covered in order to measure the quality of palliative care. According to a previous international systematic review to identify existing quality indicators in palliative care, the psychosocial and spiritual domains were underrepresented (61). Our update of that review showed only a small increase of indicators in both domains (62), not adhering to the recommendations made by Pasman et al. in their review to pay extra attention to the development of quality indicators for social and spiritual aspects of care. The quality indicator set that was developed within the scope of this thesis meets these recommendations as all domains are well represented (table 1).

Table 1: representation of the nine quality domains in the indicator set

Domain of quality palliative care	**N° of QI**
1. Physical treatment and care	11
2. Psychological, social and existential treatment and care	16
3. Information, communication , planning and decision making with patients	20
4. Information, communication , planning and decision making with family	6
5. Information, communication , planning and decision making with other caregivers	3
6. Type of care at the end of life	6
7. Coordination and continuity of care	9
8. Support of family and informal caregivers	9
9. Structure of care	4
TOTAL n° of QI	**84**

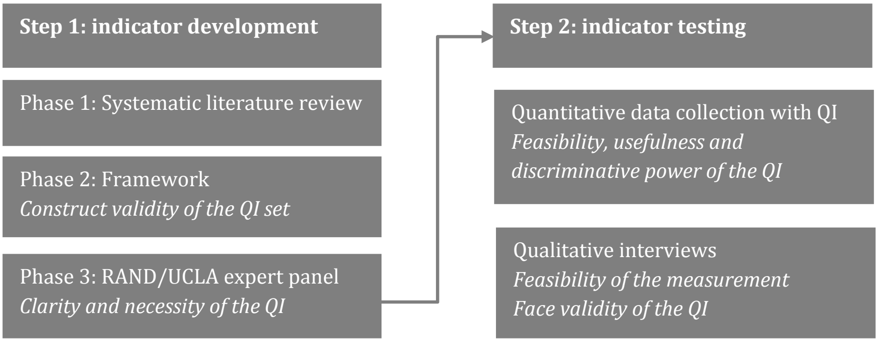
Another distinguishing feature that contributed to the comprehensiveness and face-validity of the indicator set is the involvement of all important stakeholders from the very beginning of the development process. Research points out those different stakeholders have different perspectives on what is important when measuring the quality of care (48-50;63;64). Patients, next of kin and professional caregivers emphasize different aspects of care when asked what is important to take into account when measuring the quality of palliative care. All these elements can best be taken into account to be as comprehensive as possible but also to increase the face-validity of the set. Instead of using only administrative data and patient records to collect the necessary data, we chose to translate the indicator set into questionnaires for different responder groups (i.e. patients, family members and professional carers), so that the indicator set was not limited to only those aspects that are recorded for administrative purposes and every stakeholder would have a voice in the quality monitoring. Hence information on satisfaction of users is combined with experiences of professional caregivers to improve the quality of care.

We succeeded in developing a comprehensive quality indicator set that can be used in all specialized palliative care services in Belgium. Whereas other quality indicator sets for palliative care focus on specific patient populations or specific care settings (63;65-67), we wanted to develop generic indicators for the whole field of palliative care. The advantage of such generic indicators is that they more easily allow comparison between the different types of palliative services, after identifying the necessary case mix adjusters. Some authors choose not to develop generic process indicators because they are better used to assess disease specific care and because they need regular updating (68). In another development trajectory focused on quality indicators for cancer care, the researchers observed that next to generic outcome indicators, there are possibilities to develop generic process indicators as well (43). In this thesis, we managed to develop generic outcome, process and structure indicators, giving additional value to our indicator set.

For our feasibility study, we decided to combine quantitative and qualitative research to test the indicators' face validity, feasibility, usefulness and discriminative power and the measurement procedure's feasibility. Therefore, the quality indicators were used by caregivers in 9 different palliative care services. We choose to test the indicators in a rather small field because it is better to first pilot test in a smaller population before implementing at wide scale. We could closely follow the testing process so that we could evaluate which aspects would facilitate or impede the use of the indicators. No protocols have been published on how to validate quality indicators in palliative care (43;69;70). However the framework and indicator testing protocol published by Campbell et al. aimed at validating quality indicators for general health care provided a useful basis (71). It states that use of the RAND/UCLA method in a first stage guarantees clarity and necessity of the indicators. In a second stage the quality indicators then need to be tested making use of a combination of methods: 1) data extraction to test feasibility of the indicators, and 2) interviews with caregivers to test the workload, face validity and implementation issues.

The following of these steps in our development project can be considered as strength. The mixed method design for the feasibility testing contributes to a standardized framework and indicator testing protocol for indicators in palliative care that can be used by other researchers in different countries (figure 3).

Figure 3: Standardized indicator testing protocol for generic quality indicators in palliative care



Until now, little was known about conditions that might facilitate or impede implementation of new innovations into palliative care services. The qualitative research we performed with palliative caregivers was the first to identify factors related to successful implementation of quality indicators into palliative care. By using the focus group method, we were able to analyze in depth which conditions need to be tackled in order to successfully implement the quality indicators into the palliative care services. Although three focus group interviews were held, representing the three types of palliative care services (multidisciplinary palliative home care teams, palliative care units and multidisciplinary mobile palliative care teams) we only took into account the perspectives of the palliative caregivers. This led to the identification of barriers and facilitators mostly linked to organizational structures and motivational aspects. Once implementation has started, further evaluation will be possible in order to overlook additional barriers and facilitators on more local level linked to the social context of care (72).

Methodological limitations

An important limitation of our indicator set is that it is, for reasons of feasibility and applicability, limited to only specialized palliative care services. It could be argued that relevant information on quality of palliative care will be lost when focusing only on specialized palliative care services. On the other hand a well-known problem in palliative care research is the difficulty to define the palliative patient (73). By focusing the quality measurement on all specialized palliative care services, all patients making use of such a service are involved. This is almost half of the palliative patient population (74;75). Furthermore the services will have the opportunity to use the quality indicators for internal quality monitoring and improvement. However, a challenge remains to measure the quality of care for all patients with palliative needs, also those not making use of a specialized service.

During the development process, the RAND/UCLA method was used to select appropriate indicators for palliative care (phase 3). One limitation in our study was that the experts who participated in the selection procedure had no experience at all with the RAND/UCLA scoring process. This was reflected in the fact that all indicators obtained very high scores on appropriateness and necessity. Therefore we had to adapt the indicator selection method in order to distinguish between appropriate and less appropriate indicators. It is almost impossible to compose a multidisciplinary expert panel in palliative care only with experienced experts. Nevertheless the problem could have been partly solved by better defining the scores and giving examples to guide the unexperienced experts in the scoring process.

The feasibility study (phase 4) was done in 9 palliative care services that volunteered to participate. These can be seen as forerunners and may not be representative to all palliative care services. Still, when starting to test and implement quality indicators in the field, relying on forerunners will put an example and share experiences with other caregivers (76). Nevertheless, further testing and validating of the quality indicators in large populations is necessary in order to prove feasibility, effectiveness and discriminative power of the indicator on national level.

In our study we could only evaluate construct validity, feasibility, usefulness, face validity and discriminative power of the quality indicators. We could not yet examine the criterion validity, i.e. the correlation between the different quality indicators, and case mix stability, i.e. the influence of patient characteristics on the quality indicator scores. Much larger databases are needed to perform such analyses (43).

Discussion of the findings in the light of current challenges and state of affairs within end-of-life care research

Towards quality improvement in palliative care

Now that a comprehensive quality indicator set has been developed and found feasible for quality assessment in palliative care, the next step towards quality improvement is the merging of both experiences from research and practice. The past two decades, palliative care research has been advancing towards the documentation of assessment tools and interventions that can improve patient outcomes and reduce the costs of care (77). In order to advance the practice of palliative care parallel with these advances made in research, we need to implement the evidence-base extracted from research into practice, not only to support and direct palliative care but also to enhance changes in practice and hence improvement of palliative care (78;79). Until now evidence-based palliative care has been largely absent (79-85), but that does not mean that services are not effective. We just do not know how services are performing in terms of high quality palliative care. Therefore current priorities in palliative care are to develop standards and indicators that will apply on all palliative care services and to evaluate all aspects of quality palliative care, including those not yet evaluated (82;86)(54;55).

State of affairs in quality improvement initiatives within end-of-life care

In order to prove the scientific value of the quality indicator set developed within the scope of this thesis, the strengths of the methods used and the results achieved within this PhD thesis will be further highlighted in line with the state of affairs in international quality improvement initiatives.

In this thesis a research group, in cooperation with a national palliative care organization, took the initiative to develop a quality indicator set for palliative care services to systematically monitor the quality of care. At long term the quality indicator set should be implemented in order to start a national quality registration and benchmarking within palliative care. In other countries that are already using a national quality registration system within end-of-life care, the quality improvement initiative was usually taken by the government (42;87-91) leading to some different challenges and results. Administrators from Canada, the U.K., Australia, Sweden and the Netherlands incorporated the quality improvement initiative into their policies and strategies. In this way development of national quality markers, indicators and benchmarks was established. Still, these quality markers and indicators are in many ways different from our quality indicator set.

Already in 2002 (before the start of this thesis) the Canadian government established 'The Canadian Strategy on Palliative and End-of-Life Care' (88). One of the working groups within this strategy focused on 'best practices and quality care' in order to promote, facilitate and coordinate activities related to improving the quality of palliative and end-of-life care. This working group developed and implemented a core set of 5 performance measures to support accreditation of hospice and palliative care. Participating health organizations were required to use this core set to measure their performance, and to report the results to an external organization.

The aim of the performance measures was rather to see whether organization met the national standards than to use the measures for internal evaluation and improvement of care within the organizations. In this way the performance measures differ from our indicator set, as our indicator set is mainly meant for such internal use by the specialized palliative care services. This is an important goal as we learned from our focus group interviews (chapter 6) that palliative care services are searching for a tool to measure and improve the effects of the quality improvement trajectories and they are willing to use the quality indicators for this purpose. Therefore having developed a tool for internal quality monitoring is of high value for palliative care practice, although future external use of the indicators remains an important secondary goal.

In 2008, the U.K. government published an 'End of Life Care Strategy' for all adults with advanced progressive illness and care given in all settings (90). As a result of this program, different care pathways were developed and implemented (the Gold Standards Framework, Preferred Priorities for Care and the Liverpool Care Pathway for the Dying Patient). Based on the data gathered with these pathways, a number of quality markers for various settings (primary care, hospitals, care homes, specialist palliative care, ambulant services and out of hours medical services) were identified (92). These quality markers were based on structures and processes of care and were meant for external use, i.e. benchmarking the quality of palliative care in the U.K. (similar to the performance measures in Canada). Outcomes of care have not yet been included in the quality markers.

Because the quality markers were primarily based on existing data collections (via the pathways) instead of a well-defined framework of domains in quality palliative care, the set of markers is not as comprehensive as should be to evaluate overall quality of palliative care. On the contrary our indicator set shows this comprehensiveness, because we developed the indicators before starting a national quality registration within the field of palliative care in

Belgium. Moreover, since different quality markers were developed for different settings, it will be difficult to benchmark quality data across all these different settings in the U.K. The indicator set that was developed within the scope of this thesis has the future opportunity to be used externally in order to identify benchmarks and compare quality of palliative care across different types of settings and services. This is an important secondary goal of the indicator set as receiving benchmark data is seen by the Belgian palliative caregivers as an important facilitating condition to be using the quality indicators within their service (chapter 6). They are especially interested in benchmark data because they want to learn from each other's specialties to improve their own care. This may create an important opportunity for the implementation of the indicators in practice.

In 2010 the Australian government endorsed a National Palliative Care strategy covering four goal areas: awareness and understanding, appropriateness and effectiveness, leadership and governance and last capacity and capability (87). One of the underlying projects was the 'palliative care outcomes collaboration' (PCOC) focusing on outcomes of care only (opposite to the quality markers of the UK). This project provided a national framework for palliative care services to assist them in collecting information about patient outcomes in order to evaluate, compare and improve the quality of their service (93). On short notice, they managed to set up a national quality monitoring system with almost 80% of specialist palliative care services cooperating. Still they did not use well-defined quality indicators to evaluate palliative care. Moreover they focused on the benchmarking of outcomes only. The indicator set we developed takes into account structure, process and outcome indicators at the same time, creating the opportunity for caregivers to get more insight in how structures, processes and outcomes together have influence on the quality of care within their service. The feasibility study (chapter 4) of the indicators showed that measuring structure, process and outcome of care is feasible and useful for the services. In the light of the previous finding regarding being interested in benchmark data, it is very useful to be able to compare structure, process as well as outcome measurement, in order to learn from each other's care structures and processes.

In Sweden, not as a result of a national improvement strategy but as initiative of the Swedish association for Palliative Medicine, a nationwide quality register was started for palliative care in 2004 (91). The goal of this register was to achieve details about every death in Sweden. Therefore care units needed to register every death within their unit on a website and complete an online questionnaire. Based on the data retrieved in this register, eight quality indicators of good end-of-life care were identified. Feedback was given to the services immediately after registration. This is again different than in our project, as the Swedish quality indicators were developed based on the data that were already gathered. A pilot study with the national register and the eight quality indicators showed that a significant improvement of end of life care was achieved within the services over three year period of registration and receiving feedback (94).

These results were promising although it was not possible to conduct a comprehensive evaluation of the overall quality of palliative care based in these indicators, as they did not cover all domains of palliative care. Another important difference with our quality indicators is that only the perspective of the caregiver has been taken into account, whereas we decided to involve the point of view on quality of care of all stakeholders (patients, family and caregivers). When measuring quality of care from four different perspectives, it is possible to combine information on user satisfaction with information redrawn from the patient files by the caregivers. As our measurement procedure to do so has been found feasible by the caregivers (chapter 4), this finding is of high value for future international quality monitoring projects.

To conclude, all four countries established a national registry system to collect information on end of life care practices in their countries starting from a national strategy in end of life care. Although within every project feedback was given to the participating services on the quality scores and benchmarks achieved, in neither Canada nor U.K. was the first goal to let palliative care services use the standards or indicators for internal evaluation and improvement of their care. More substantially, none of the projects seemed to aim for a level of comprehensiveness that is necessary to evaluate the various dimensions of quality of palliative care. Moreover, few details on the development trajectories and measurement procedures of the standards and indicators were published, making it difficult to understand to rationale behind it and to use the ideas and techniques within other similar projects. The development trajectory of quality indicators for palliative care used within the scope of this thesis is one of the first complete trajectories published in the international palliative care research field, besides the Dutch trajectory (69). The framework and indicator testing protocol that we used within the scope of this thesis (presented in figure 3) can be applied by other researchers and administrators in different countries striving for high quality palliative care within their palliative care services.

In 2008, the Dutch government made a policy statement, stressing the need for a set of quality indicators focusing on patient outcomes and applicable for all palliative care settings (home, hospice, palliative care units, nursing homes, homes for elderly, mental health institutions and institutes for mentally retarded) (95)(96). The quality indicator set should in the first place serve for internal use within the health care organizations, but also should have the potential to be applicable for external use as is the case with our quality indicator set. This led to a similar development project as the one described in this thesis, resulting in a generic outcome indicator set with 33 indicators for palliative patient care and 10 indicators for support for relatives before and after the patient's death (42;69). Although a similar development method was used and the indicator set was also meant for broad use, covering all domains inherent to palliative care, some differences exist with the indicator set we developed. Firstly the Dutch indicator set focused only on outcome, restricting palliative care services in the quality evaluation as they lack information on structures and processes of their care. Furthermore the quality indicator project described within this thesis did not start as an initiative from the Belgian government but was initiated by the research group together with the Palliative Care Federation Flanders. Hence no restrictions were imposed on how to develop the quality indicators.

If we bear in mind the six dimensions of quality of care the WHO introduced (97), we can conclude that our indicator set has the ability to evaluate or address (aspects of) all of these dimensions once it is implemented within palliative practice (table 2). Since our indicator set can provide the necessary evidence-base for quality improvement within palliative care services, it can be used to achieve a higher *effectiveness of care* for patients and families. When benchmark data will be available for comparison between and across different types of palliative care services, patient characteristics can additionally be taken into account in order to improve the *equitability of care*. Also, these patient characteristics can be used to enlarge *accessibility of care*, by combining them with the quality indicator score about timeliness of palliative care (incorporated in the quality indicator set). Because of the comprehensive character of the indicator set, it can provide quality data on structures, processes as well as outcomes of palliative care. These results can be used to evolve towards *safer and more efficient care* as existing structures and processes can be evaluated and changed in order to retrieve better outcomes of care. Furthermore, patients' and families' preferences, aspirations, needs and values are taken into account when monitoring the quality of care using the indicator set. Hence it will be possible to measure whether these preferences and needs were met. This will add to the *patient-centeredness of care* within the palliative care services.

Table 2: The contribution of our indicator set to the six dimensions of quality of care

Dimension of quality	Description
Effectiveness of care	Our indicator set can provide the necessary evidence-base to improve the outcomes of quality, taking into account the needs of patients and family
Efficiency of care	Our indicator set provides a systematic procedure to continuously evaluate the quality; the quality results can be used to evolve towards efficient care
Accessibility of care	Our indicator set measures the timeliness of palliative care and has the ability to improve the accessibility of care
Patient-centeredness of care	Our indicator set measures whether patients' and families' preferences, aspirations, needs and values were met
Equitability of care	The results of the quality indicators can be benchmarked in order to compare quality of care over different services in order to make it equitable
Safety	Our indicator set can be used to evaluate structures and processes of care in order to improve safety for palliative patients

Implications for policy, practice and research

Now that a comprehensive and valid indicator set has been developed for palliative care, specialized palliative care services are able to use it for internal quality assessment and improvement. Since the beginning of this PhD trajectory, quality indicators are already used more frequently and in more countries (e.g. The Netherlands, Germany, and Japan) illustrating the evolution of research and practice in palliative care an international level. Considering the raising importance of palliative care in our society, it is not only important that policy makers in different countries should invest in palliative care oriented programs to monitor and improve the quality on a national (and eventually even international) level. The quality indicator set can be used in national and international palliative care improvement strategies in order to systematically and continuously monitor quality of palliative care for patients and their families. To guarantee that the quality indicators are being used for its right purpose, we formulated some challenges and recommendations for all researchers, caregivers, administrators and policy makers who want to apply quality indicators to guarantee high quality palliative care.

Challenges and recommendations for policy makers

In 2000 the Government in Belgium made some efforts by setting out a policy that focused on the deliverance of appropriate support and increasing access to palliative care, resulting in a law on palliative care in 2002 (98;99). Until now, it did not yet focus on the quality monitoring and improvement that is necessary to guarantee high quality palliative care for Belgian patients and their families. Therefore policy makers in Belgium, but also those in other countries not yet performing quality monitoring in palliative care, need to be encouraged to set out **a national improvement strategy for palliative care**. To make such a strategy successful it should comprise several goals (table 3).

Table 3 A national improvement strategy for palliative care in Belgium and in other countries

Strategy goal	Tasks for policy makers
Implementing a quality monitoring system	Implement quality indicators into palliative care services, but also in other settings e.g. family medicine, oncology, geriatrics and pediatrics
Building a database with quality results	Gather all registration data and quality indicator scores in one national database; identify case mix adjusters to benchmark quality results
Setting up a national improvement trajectory	Identify possible improvement actions for palliative care; implement these actions and measure the effect of improvement over time
Making quality results transparent	Communicate quality indicator results and benchmark data in research reports, policy papers, on public websites and on international level

The first goal of a national improvement strategy would be to *implement a quality monitoring system,* by implementing the quality indicator set that was developed during this PhD trajectory into all palliative care services. . Together with this large scale implementation the quality indicators should be further tested for feasibility and discriminative power for large populations, as national quality data will be available. This can best be done in close cooperation with the research field. Next to implementation in Flanders, there should be a similar project in Wallonia, the French speaking part of Belgium, to be able to monitor and evaluate quality of palliative care on national level. Next, it would be important to eventually also go beyond specialized palliative care services and to adapt the indicators and develop a similar quality indicator set for monitoring palliative care that is provided within other health care settings such as family medicine, oncology, geriatrics and pediatrics.

Implementing such a new innovation as the comprehensive quality indicator set for palliative care evokes specific challenges for administrators and policy makers. The first and most important challenge will be to motivate and convince palliative managers and caregivers of the usefulness and utility of the quality indicator set. Only then will it be possible that the quality indicator set will be successfully used by several palliative care services in Flanders. Our focus group study indicated that the field of palliative care is ready for implementation of quality indicators. Several palliative care teams indicated that they were already looking for a reliable tool to capture the quality of their care. Furthermore they have an eager to share quality results between the different palliative teams and learn from each other in order to improve their practice. They are willing to make their quality scores public and to benchmark them on national level so that patients and families can benefit from high quality palliative care. Therefore administrators should take these opportunities to start working on a national and systematic quality monitoring within the field of palliative care.

Besides taking into account attitudes and experiences of palliative managers and caregivers when implementing the quality indicators, it is also necessary to continue to involve all other possible stakeholders when progressing towards a systematic use of the quality indicators in palliative care. It is interesting to set op partnerships in order to increase the familiarity and use of the quality indicators in practice (76). Organizations that can be considered for such partnership are for example national palliative care federations, patient organizations and palliative care networks. Such organizations can be asked to reside into a strategic advisory board. Through this board different stakeholders will be able to formulate policy recommendations and to control the implementation and systematization of quality measurement in palliative care. In this way caregivers as well as patients can be protected from unintended side effects such as the progressions towards a rewarding system with the quality results instead of an improvement trajectory. On the other hand, close cooperation with research teams is needed in all this to safeguard the scientific value of the implementation process and quality monitoring. Palliative care teams will be less suspicious and probably more cooperative if quality indicator projects are conducted by independent research teams rather than administrators also involved in policy making and funding arrangements.

In order to progress towards a systematic quality monitoring and improvement system, the second goal of a national improvement strategy would comprise *the building of a large database* with all quality measures in palliative care. This database should combine all registration data on transfers and access with the quality indicator scores. Such a large database gives policy makers, in cooperation with researchers, the possibility to benchmark quality data and compare quality of care over time and services. In order to be able to benchmark, patient mix confounders should identified in cooperation with experts so that just comparison is possible and best practices can be exposed. These benchmarks take into account confounding patient characteristics in order to make fair comparison of quality of care between and across different types of palliative care services possible.

The third goal of the national improvement strategy builds on the best practices that can be identified through the quality measurement. It is important that policy makers share these best practices in order to inform palliative care services on the improvement possibilities. Policy makers can then help services to improve their practice to set out several improvement trajectories in palliative care. In cooperation with the research field, policy makers should *identify and present possible improvement actions* that can be implemented by the palliative care services. After implementation the improvement effect can then be measured by making use of the quality indicators and database (100).

Fourth and last, it would be important *to make the quality of care transparent* to the different stakeholders. This can be done by reporting the quality indicator scores and benchmark data in research reports, policy papers and on public websites (69). In this way palliative managers' and caregivers' awareness of the importance to improve quality of care on an evidence basis can be increased. Also patients and families would be encouraged to think more critically about their preferred place of care and other wishes and possibilities in their end of life care trajectory. Furthermore researchers and administrators in other countries could be informed about the state of affairs in palliative care worldwide. Moreover we recommend governments of different countries to develop an international strategy for palliative care. This should also include the identification of an international minimal data set that can be used to benchmark between countries and hence improve the quality of palliative care on international level (101).

Although transparency and benchmarking of quality indicator results are effective strategies to improve awareness and quality of care on national and international level (68;102-106), policy makers must remain thoughtful about when and where quality indicator results are publicly published. Caregivers should never feel accused for the quality results obtained or feel helpless in overcoming them. Instead they should be encouraged to use these results to evaluate their proceedings in a critical manner and take action to improve the care. To do so it could be helpful to appoint trainees on a national level to visit palliative care services and help to set out a yearly working plan based on the quality monitoring. These trainees should be trained themselves first ('train the trainer') in helping palliative care services setting out improvement trajectories with the quality indicator results. Also patients and families should be guided wisely in interpreting quality results and using them for making their own choices, for instance by publishing a 'choice guide' to help patients directing their own care trajectory together with their caregivers and family. Last we advise against the use of quality indicator results to structure the distribution of resources or funding of the palliative care services (107). A link between quality scores and funding may have adverse effects on the quality of care, e.g. caregivers will possibly not improve the care for the patients, but rather change practices in order to receive the full benefit of the government. Therefore administrators should prefer funding the palliative care providers for using the quality indicators for improvement efforts so that patients, caregivers and policy makers can fully benefit from the systematic quality monitoring system (108).

To summarize, the quality indicator set that was developed within the scope of this thesis has a great potential for policy makers. Quality indicators can provide the necessary information on performance of the palliative care services to improve the quality of palliative care on a national level. Nevertheless it remains important to *create an optimal environment* that is needed to measure and apply the quality indicators (86). In other words, palliative caregivers and managers should be fully supported (morally as well as structurally) by the government in order to make systematic monitoring of quality within their services possible. Based on our focus group study that is presented in chapter six, we know that the right conditions for caregivers can be created by providing knowledge on the use of quality indicators within improvement trajectories, by providing time and personnel to perform the quality measurements and by applying the quality results in regional and national improvement meetings. Moreover with these structural changes, quality measurement and improvement could become part of the daily palliative practice. This is a necessary condition if one aims for successful quality improvement

(107). Therefore it remains important for policy makers to keep investigating how they can contribute to meet the needs of the managers and caregivers to conduct quality evaluation and improvement repeatedly within their services. This can be done by incorporating the quality indicators within the existing registration and by foreseeing web based applications to report the quality indicator scores in order to enhance the user-friendliness of the quality indicators and hence reduce the work load for palliative caregivers. Once such a systematic quality monitoring system has been enrolled within the field of palliative care, it remains a challenge to further investigate which structural improvements are needed for the palliative care services and caregivers to maintain high quality palliative care on a national level.

Challenges and recommendations for practice

The quality indicator set that has been developed during the PhD trajectory is ready to be used by individual palliative care services in Flanders, Belgium. It has the opportunity to evaluate and improve the quality of care within the service, on the condition that the quality indicators are regularly measured and all quality indicator scores will be gathered in a database so that improvement over time can be monitored. We recommend that every service measures the quality indicators twice a year in order to gather representative quality information about the care delivered. For the hospital based services, we recommend one extra measurement per year only involving the patients under guidance in order to enlarge the population and hence the generalizability of the data. To succeed in such regular measurements, it can be helpful to plan each measurement moment well in advance.

Since it is not only important to evaluate the quality of care but also to improve it, the use of quality indicators can best be embedding into a general circle of improvement. This means that after the quality indicator set has been implemented and measured for the first time, the coordinator and his team need to take up the responsibility to interpret the quality indicator scores and distillate working point for the team. To do so, the team has to bear in mind that quality indicators have a signaling function (69). This means that when a certain indicator score may lead to poor quality of care, the team members need to discuss what could be at the basis of this result. For example, when the indicator scores show that more patients than the caregivers had expected are experiencing moderate to severe pain, they need to take into account the processes and structures regarding pain assessment and treatment within their service. Additionally they also have to take into account the characteristics of the patient population and unforeseen circumstances such as instabilities within the team at the time of the quality measurement or other incidents that might have influenced the quality results of the team.

When the team members have agreed on possible explanations on what might have caused these high scores on pain they can then together decide if action needs to be taken to improve this outcome. Next, when the team has decided on all working points, the coordinator can draw up actions in order to address these working points. For instance if the team decided to work on informing patients and families, the coordinator can organize a group discussion on how to properly inform patients and families. Another example of an action to address this theme is a role play in which caregivers have to inform patients and family members with different information needs on several topics.

Last, it should be safeguarded that quality improvement actions never influence other areas of care where quality was already high. Hence besides discussing working points, the team members also have to discuss how to maintain the existing quality in order to progress towards overall high quality of care for their patients.

Challenges and recommendations for future research and implementation

The quality indicator set that is developed for palliative care services is ready to be used in large scale national quality monitoring and improvement programs. Therefore the quality indicators need to be implemented in the field of palliative care. The implementation of the quality indicators will lead to the building of a large database of quality indicator scores for several palliative care services and about thousands of patients and family members. Based on such a database, important analyses can be performed. First the quality indicators can be further tested and validated for large populations so that the feasibility of the indicators on a national level is guaranteed. This is necessary because until now the indicators were only tested in a small environment. Second, the discriminatory capacity of the quality indicators can be calculated to know how well a quality indicator can discriminate service providers' quality and detect changes in this quality (109;110). Next patient case-mix adjusters can be identified (46). These are needed for benchmarking and identifying the best practices in palliative care (110-112). Benchmarking is defined as the continual and collaborative discipline of measuring and comparing results of key processes with those of the best performers (113). Moreover, even beyond implementation the quality indicator set and measurement procedure should continuously be evaluated and tested for feasibility and usefulness (43). It could be that after a longer period of use, some quality indicators are no longer useful because of changes in the field or because of improvements due to the efforts made (e.g. an indicator that scores 100% in all services is no longer a good indicator). If appears that an indicator does no longer show enough discriminative power or improvement possibilities, it should be discarded from the set immediately. Furthermore it may be that new advances within the field of palliative care imply the development of new quality indicators. Regularly performing literature searches and updates of systematic literature reviews on existing indicators can then be helpful. Also, by asking experts on a regular basis for feedback, the existing indicator set can be updated if necessary (114). For example, a website can be opened where experts may give feedback on the existing indicators and may suggest eventual need updating (43).

Furthermore for researchers in other countries who decide to develop a quality indicator set for palliative care, we can recommend using the indicator development and testing method described extensively in this thesis. In step 1, when aiming for the composition of a suitable quality indicator set for quality monitoring in a country, it remains interesting to start with searching for existing international quality indicator sets. From the literature we know that already many indicators are developed for the field of palliative care (61;62). Therefore this existing evidence can best be used to select and develop quality indicators for other countries. It is known that quality indicators can be adapted to the specific structure and organization of palliative care of a country (115). By involving experts during this process, specific needs can be identified, indicators can be judged on usefulness and new indicators can be developed if deemed necessary. Hence a new comprehensive quality indicator set can perfectly be composed of existing quality indicators completed with own developed indicators. Nevertheless it remains important to validate the adapted indicators, even if they were already validated in other countries. We also recommend each research team that is going to develop indicators to involve all stakeholders from the start of the process. It is even possible to set up national and international research collaborations with researchers experienced in quality indicator development for palliative care to exchange experiences and information. Furthermore, a steering group with all stakeholder representatives (researchers, caregivers, administrators, policy makers and consumer representatives) can be assembled. The steering group has to be consulted regularly in the development process about the validity of the chosen indicators and the further steps that need to be taken to progress towards a systematic quality monitoring and improvement program in the country. Only then the use of the quality indicators for the right purposes can be guaranteed.

The way forward

The quality indicator set within this thesis is primarily meant for internal quality evaluation and improvement by specialized palliative care services in Flanders, Belgium. Nevertheless wide implementation of the quality indicator set can offer some opportunities for external use, such as monitoring quality of palliative care at national level, benchmarking data and comparing quality between the different palliative care services and setting out national improvement trajectories within palliative care. Before such external use is possible, the quality indicator set needs to be further validated for large patient populations in terms of feasibility, usefulness and discriminative power. This implies that the development and validation process described in this thesis is only the beginning of a long road towards actual innovation within palliative care. The way forwards is still long but many opportunities lie ahead, on the condition that every further step in the use of the quality indicators will be well considered and well prepared. I will discuss some future opportunities for internal as well as external use of the quality indicator set and the accompanying hurdles.

For now, the quality indicator set is ready to be used by different palliative care teams in Flanders for **internal evaluation**. This means that the palliative care teams can repeatedly measure the quality indicators following the standard procedure and use the quality indicator scores for evaluation of the care they delivered (see also 8.4.2 challenges and recommendations for practice). In order to make it possible for the palliative care teams to successfully use the quality indicators for internal evaluation, we deemed it important to **develop a strong implementation plan** that fits the needs of the caregivers and palliative care teams (76;110). This plan can convince and support palliative care teams to start using the quality indicators in their service for internal evaluation of care. It is important that such a plan contains a combination of several implementation strategies to overcome possible barriers as well as to intensify the facilitating conditions. At first, to provide caregivers with the necessary knowledge and skills to use the quality indicators, palliative caregivers from cooperating palliative care services need to be trained intensively. Table 4 gives an overview of the possible content of such training in three modules of one hour each. After this training the coordinators need to be encouraged to involve all team members and inform them about the use of the quality indicators and the purpose. Another important step towards successful use of the indicators is the delivery of all necessary documents and information (manual, questionnaires, informed consents, and data input tool) to the coordinator of the team. Only then the team will be able to conduct the measurement procedure of the quality indicators correctly.

Table 4 Overview of the possible content of training on quality indicators for palliative caregivers

Modules	Content	Aim
1. What are quality indicators (QI) and how are they measured? (1 hour)	➢ Definition and examples ➢ Why they are needed ➢ How to calculate ➢ The measurement procedure	Caregivers can now: ➢ Explain 'QI' ➢ Explain how to measure them
2. How are QI used to monitor and improve the quality of care? (1 hour)	➢ How to interpret QI scores (with examples) ➢ How to distillate working points ➢ How to take action	Caregivers can now: ➢ Interpret QI scores in order to prioritize improvement goals (in team)
3. How can I successfully implement the QI into my service? (1 hour)	➢ How to motivate team members ➢ Possible problems and solutions ➢ Approaching patients and family ➢ Some implementation strategies	Caregivers can now: ➢ Identify and solve problems ➢ Explain what needs to be done to implement the QI

Once different palliative care teams start using the quality indicators voluntarily, based on a well-considered implementation plan, **process evaluation** is needed to evaluate the quality of the implementation process, the effectiveness of the strategies and to identify additional barriers and facilitators and hence additional implementation strategies (76;110). This can be done by collecting and analyzing feedback from the caregivers using qualitative techniques such as logbooks, feedback forms and interviews with all persons involved in the measurement. In this way the caregivers can exchange experiences with the researchers, and the researchers can evaluate whether the implementation steps where followed correctly, whether the strategies were useful and whether new barriers and facilitators occurred. Only by closely monitoring the implementation process in a natural setting, one can be fully aware of the impact of the quality measurement for the team and everyone involved with it (ref).

Quality indicators are only useful and effective if they can be applied to **enhance and improve patient care**. The best way to establish change in patient care by using quality indicators is to set out improvement trajectories. This can already be done on internal basis, i.e. individual palliative care services set out improvement action and measure the effects with the quality indicators using a pre- and post-measurement. On external basis, improvement in patient care can be reached by setting out national improvement trajectories. In the Netherlands, best practices such as the Liverpool Care Pathway and The Gold Standards Framework are being implemented into several palliative care services in order to improve the care on a national level. To do so, a quality indicator set for palliative care is used for effect evaluation. This means that the quality indicators are measured with patients and bereaved relatives in order to measure the effect of the best practices in terms of quality improvement in palliative care. From now on, such initiatives are possible for Flanders on the condition that best practices for palliative care are selected and that, at the same time, the quality indicator set is further validated in terms of usefulness and feasibility.

Until now, little is known about the influence of the use of quality indicators on patient and family outcomes in palliative care. Only one study in Sweden reported improved outcomes for patients over a period of 3 years after giving feedback to services about eight quality indicators based on a national death registry with retrospective data collected by professionals. From these results we can conclude that care processes change and improve when using quality indicators, but the effect on patient and family reported outcomes is still unknown. Therefore, more research is needed into the effects of using quality indicators and benchmarks on patient and family outcomes for quality improvement in palliative care. Our quality indicator set provides a good basis for such large scale effect analysis.

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Samenvatting van de belangrijkste bevindingen

Achtergrond

Kubler-Ross, Cicely Saunders en andere invloedrijke thanatologen spraken in hun wetenschappelijk werk reeds over de kwaliteit van zorg voor de stervende patiënt. De palliatieve zorg-beweging kwam op vanaf 1960 en verspreidde zich gestaag over verschillende landen. Op dit moment wordt zorg voor de ongeneeslijke zieke patiënt in de meeste Westerse landen aangeboden door gespecialiseerde palliatieve zorginitatieven. Deze zorginitiatieven omvatten meestal palliatieve thuiszorgequipes, alsook palliatieve teams in ziekenhuizen en palliatieve eenheden. Het wordt voor hen steeds pertinenter om de kwaliteit van de geleverde zorg te bewijzen en verbeteriniatieven te evalueren. Vele organisaties stelen zich regelmatig vragen als: “Hoe kunnen we laten zien dat we kwaliteitsvolle zorg leveren?”, “welke aspecten van onze zorg hebben verbetering nodig?”en “hoe kunnen we hier succesvol in zijn?”.

Toch ligt palliatieve zorg ver achter op de andere domeinen en de gezondheidszorg wat betreftsystematische kwaliteitsevaluaties en verbeterinitiatieven. Hoewel veel palliatieve teams bezig zijn met de kwaliteit van hun zorg, baseren ze deze evaluaties nog te vaak op veronderstellingen en subjectieve gevoelens over wat de patiënten en hun familie belangrijk vinden in de zorg. Het blijft daarom een uitdaging voor de palliatieve zorg om de kwaliteit van zorg op een systematische en valide maniet te meten en evalueren, zodat de resultaten gebruikt kunnen worden om de zorg te verbeteren daar waar nodig. Kwaliteit van palliatieve zorg kan het best gemeten worden aan de hand van kwaliteitsindicatoren. Dit zijn meetbare onderdelen van de zorg die ons iets vertellen over zowel structuren, processes als uitkomsten van de zorg. Ze worden uitgedrukt in een percentage en bestaan uit een duidelijk gedefinieerde teller en noemer (tabel 1). Kwaliteitsindicatoren kunnen gebruikt worden om de zorg te verbeteren binnen de verschillende palliatieve zorgvoorzieningen, omdat ze een aanwijzing kunnen geven aan de zorgverleners van welke aspecten van de zorg goed verlopen en welke minder goed verlopen en dus ruimte hebben voor verbetering.

Tabel 1: Voorbeeld van een kwaliteitsindicatoren met teller en noemer uit de Vlaamse set

Teller	Aantal patiënten van wie de algemene symptoomlast werd geëvalueerd op een gevalideerde schaal	145
Noemer	Totaal aantal patiënten bij wie deze indicator werd gemeten	200
	Indicator score	73%

Omdat palliatieve zorg een multidimensionele benadering hanteert, waarbij er zowel oog is voor de patiënt en zijn familie, als voor verschillende aspecten die invloed hebben op kwaliteit van leven (fysieke, psychologische, sociale en spirituele dimensie) dienen – zo argumenteer ik in mijn proefschrift- de kwaliteitsindicatoren voor palliatieve zorg deze dimensies ook te weerspiegelen. Voor de Vlaamse palliatieve zorgvoorzieningen werd tot nu toe nog geen enkele indicatoren set ontwikkeld die kan gebruikt worden voor het monitoren en verbeteren van de palliatieve zorg.

Doel en onderzoeksvragen

In deze doctoraatsthesis werd een comprehensieve kwaliteitsindicatoren set ontwikkeld, uitgetest in de praktijk en klaargemaakt voor verdere implementatie in de palliatieve zorgvoorzieningen in Vlaanderen. De kwaliteitsindicatoren set omvat de verschillende domeinen van palliatieve zorg en werd ontwikkeld aan de hand van een wetenschappelijk robuuste methode. Deze methode omvatte 3 stappen en impliceerde een aantal onderzoeksvragen:

Stap 1: Samenstellen van een comprehensieve indicatoren set

1. Welke internationale kwaliteitsindicatoren bestaan er om kwaliteit van palliatieve zorg te meten?
2. Welke methode moeten we gebruiken om kwaliteitsindicatoren te ontwikkelen die geschikt zijn om de kwaliteit van de palliatieve zorg te meten?

Stap 2: Testen en verfijnen van de set

3. Zijn de geselecteerde kwaliteitsindicatoren voor de palliatieve zorg in Vlaanderen valide en bruikbaar?
4. Welke kwaliteitsindicatoren zijn geschikt voor een minimale set om de kwaliteit van palliatieve zorg op een snelle en efficiënte manier te meten?

Stap 3: Voorbereiden op implementatie

5. Wat zijn volgens hulpverleners mogelijke belemmerende en bevorderende factoren bij het implementeren van kwaliteitsindicatoren in de palliatieve zorgvoorzieningen in Vlaanderen?
6. Hoe kunnen de palliatieve zorgvoorzieningen de kwaliteit van hun zorg monitoren aan de hand van kwaliteitsindicatoren?

Overzicht van de resultaten

Stap 1: Samenstellen van een comprehensieve indicatoren set

Om een comprehensieve kwaliteitsindicatoren set te ontwikkelen voor de palliatieve zorg in Vlaanderen, volgden we **een proces van 3 fases**: 1) identificatie van bestaande kwaliteitsindicatoren, 2) ontwikkelen van een denkkader over kwaliteit van palliatieve zorg, 3) selectie van geschikte kwaliteitsindicatoren d.m.v. experts

Fase 1: identificatie van bestaande kwaliteitsindicatoren

In deze eerste fase van het ontwikkelingstraject hebben we gezocht naar de bestaande kwaliteitsindicatoren voor palliatieve zorg, zowel op nationaal als internationaal niveau (onderzoeksvraag 1). Hiervoor hebben we een update uitgevoerd van een **systematische literatuurstudie** die in 2007 werd uitgevoerd door Pasman en haar collega's. Onze literatuurstudie werd uitgevoerd in 2009 en gaf een overzicht van alle gepubliceerde kwaliteitsindicatoren voor palliatieve zorg die ontwikkeld werden in de periode tussen 2007 en 2009. We identificeerden 13 nieuwe publicaties bovenop de 16 uit de literatuurstudie van Pasman. In totaal konden we 17 sets van indicatoren identificeren (8 sets in 2007; 9 in 2009), goed voor 326 unieke kwaliteitsindicatoren voor de palliatieve zorg. Deze 326 indicatoren bedekten alle domeinen van palliatieve zorg, zoals geïdentificeerd door het U.S. National Consensus Project: 1) structuur en proces van zorg, 2) fysieke aspecten van zorg, 3) psychologische aspecten van zorg, 4) sociale aspecten van zorg, 5) spirituele aspecten van zorg, 6) culturele aspecten van zorg, 7) zorg voor de stervende patiënt en 8) ethische aspecten van zorg. Toch waren er slechts 2 van de 17 sets die alle 8 domeinen representeerden. Verder was het niet bij alle sets duidelijk hoe deze ontwikkeld werden en of deze reeds uitgetest werden in de praktijk.

Fase 2: ontwikkelen van een denkkader ove rkwaliteit van palliatieve zorg

In de tweede fase ontwikkelden we een denkkader zodat alle belangrijke elementen van palliatieve zorg konden meegenomen worden in de kwaliteitsmeting. Dit denkkader werd samengesteld uit verschillende denkkaders die reeds ontwikkeld waren voor palliatieve zorg vanuit het perspectief van de hulpverleners, maar ook van patiënten en familie, en omvatte 9 domeinen: 1) fysieke, 2) psychosociale en spirituele aspecten van zorg, 3) informatie, communicatie en zorgplanning met de patiënt, 4) met de familie, 5) tussen de zorgverleners onderling, 6) type van zorg, 7) coördinatie en continuïteit van zorg, 8) steun voor naasten en mantelzorgers en 9) structuur van zorg. Deze domeinen werden onderverdeeld in thema's die vervolgens werden vertaald in kwaliteitsindicatoren door gebruik te maken van de betaande kwaliteitsindicatoren die geïdentificeerd werden in het literatuuronderzoek.

Fase 3: Geschikte kwaliteitsindicatoren voor de palliatieve zorg in Vlaanderen
Deze kwaliteitsindicatoren werden gepresenteerd aan een expert panel die de indicatoren dienden te scoren op een schaal van 1 tot 9 voor bruikbaarheid en geschiktheid om kwaliteit van palliatieve zorg te meten in Vlaanderen. Uit dit expert panel kwam een comprehensieve kwaliteitsindicatoren set voort bestaande uit 85 indicatoren, verdeeld over de 9 domeinen., geschikt voor alle palliatieve zorgvoorzieningen in Vlaanderen. .

Stap 2: Testen en verfijnen van de set

In een tweede stap dienden de kwaliteitsindicatoren uitgetest te worden in de praktijk en geëvalueerd te worden voor haalbaarheid en bruikbaarheid (onderzoeksvraag 3). Het doel van de **testfase** was enerzijds om de kwaliteitsindicatoren te valideren en de bruikbaarheid van de kwaliteitsresultaten voor verbetering van de zorg na te gaan, en anderzijds om de haalbaarheid van de meetprocedure te evalueren. Daarom werd de kwaliteitsindicatoren set eenmalig gebruikt door 9 palliatieve zorgvoorzieningen: 2 mulitidisciplinaire thuisequipes, 2 palliatiev eenheden, 2 palliatieve support teams in ziekenhuizen, en 3 woonzorgcentra. Om de kwaliteitsindicatoren te meten hebben we vragenlijsten uitgestuurd naar verschillende respondenten: patiënten, hulpverleners en nabestaanden. Om validiteit, bruikbaarheid en haalbaarheid van de kwaliteitsindicatoren set te evalueren, hebben we een mix van kwantitatieve en kwalitatieve onderzoeksmethoden toegepast. Over het algemeen werd de kwaliteitsindicatoren set en meetprocedure door de hulpverleners haalbaar en bruikbaar bevonden om kwaliteit van palliatieve zorg te meten en verbeteren waar nodig. Op dit moment bestond de kwaliteitsindicatoren set uit 84 indicatoren die werden onderverdeeld in overzichtelijke thematische modules: 1) bio-psycho-sociaal-spirituele aspecten van zorg, 2) communicatie en zorgplanning, en 3) coördinatie van zorg en omstandigheden rond het overlijden.

Tijdens de kwalitatieve interviews die plaats vonden aan het einde van de testfase, gaven de meeste hulpverleners aan dat ze nood hadden aan een **minimale set** zodat ze sneller en eenvoudiger een zicht kregen op hun kwaliteit en werking. Op die manier waren er ook minder vragen nodig in de vragenlijsten. Daarom organiseerden we een expert panel om uit de 80 proces- en uitkomstindicatoren een minimale set te keizen die geschikt is om kwaliteit van palliatieve zorg in Vlaanderen te monitoren (onderzoeksvraag 4). De experten werden in een huistaak gevraagd om de kwaliteitsindicatoren te scoren op een schaal van 1 tot 9 voor prioriteit om deel uit te maken van de minimale set. Aan het einde van deze meeting werden 31 indicatoren geselecteerd, verdeeld over 4 vragenlijsten, die nog steeds de initiële domeinen van kwaliteit dekten. Daarnaast voegden we de 4 standaard te noteren structuur indicatoren toe aan de set. De overige indicatoren bleven bestaan in de 3 optioneel te meten thematische modules. U kan de volledige minimale set inclusief structuurindicatoren terug vinden in de *appendix*, in het Engels. De volledige indicatorenlijst (inclusief optionele modules) in het Nederland kan opgevraagd worden bij de auteur van dit boek.

Stap 3: Voorbereiden op implementatie

Alvorens de kwaliteitsindicatoren set geïmplenteerd kon worden in de palliatieve zorg in Vlaanderen, dienden we een aantal **belemmerende en bevorderende factoren** te identificeren (onderzoeksvraag 5). Hiervoor organiseerden we focus groep interviews met zorgverleners om na te gaan welke condities mogelijk belemmerend dan wel bevorderend zouden werken bij het gebruiken van de kwaliteitsindicatoren binnen de palliatieve zorg. Uit de focus groep interviews kwam naar voren dat de attitude van de palliatieve teams ten aanzien van kwaliteitsindicatoren en kwaliteitsmetingen maar ook de attitude, kennis en vaardigheden van de individuele hulpverleners een invloed kan uitoefenen op het al dan niet succesvol gebruiken van de indicatoren. Verder gaven de hulpverleners aan dat ze heel erg geïnteresseerd waren naar kwalitatieve gegevens en het vergelijken van kwaliteit van zorg tussen de verschillende zorginitiatieven. Deze factoren zouden dan ook het gebruik van de kwaliteitsindicatoren binnen de zorgvoorzieningen kunnen bevorderen. Op basis van deze verschillende factoren konden we specifieke implementatiestrategieën ontwikkelen, zoals het aanbieden van een training om de nodige kennis en vaardigheden bij te brengen.

Als laatste fase in het ontwikkelingsproces gaven we een **uitgebreide beschrijving van hoe de kwaliteitsindicatoren kunnen gebruikt worden** door de palliatieve zorgvoorzieningen om de kwaliteit van de zorg te verbeteren voor patiënten en hun familie (onderzoeksvraag 6). Dit is een essentiële stap in het voorbereiden van de palliatieve zorgvoorzieningen in het succesvol gebruik van de kwaliteitsindicatoren voor de juiste doeleinden.
Samengevat ziet de meetmethode voor de palliatieve zorgvoorzieningen er alsvolgt uit (figuur 1): 1) verantwoordelijke aanduiden voor de metingen, 2) dataverzameling met de kwaliteitsindicatoren door vragenlijsten te versturen, 3) data analyse door de onderzoeker, 4) resultaten interpreteren in team, 5) verbeterpunten vastleggen en actie ondernemen in team, en 6) datum prikken voor volgend meetmoment.

Figuur 1: Meetmethode van kwaliteitsindicatoren voor palliatieve zorg

Om de kwaliteitsindicatoren te meten zenden we enerzijds vragenlijsten aan patiënten onder begeleiding van een palliatief team en aan een belangrijke hulpverlener van deze patiënt; tegelijkertijd zenden we vragenlijsten aan de nabestaanden van patiënten die 4 weken tot 4 maanden geleden overleden zijn en tevens een belangrijke hulpverlener of de huisarts. Beide groepen patiënten (onder begeleiding en overlijden) worden op dezelfde dag geselecteerd. Op deze manier verzamel je tegelijkertijd informatie over processen en uitkomsten van zorg alsook over de zorg in de laatste dagen voor het overlijden (inclusief zorg en nazorg voor naasten). Na ontvangst van de ingevulde geanonimiseerde vragenlijsten, berekenen de onderzoekers alle indicator scores en geven die terug onder de vorm van een feedback rapport aan de zorgvoorziening. Vervolgens dienen de verantwoordelijken van de verschillende teams de indicator scores te bespreken en evalueren in teamverband, waarna werkpunten kunnen gedistilleerd worden voor het hele team. Op basis van deze werkpunten kan de verantwoordelijke een opleiding, groepsgesprek of een andere actie inplannen teneinde de zorg te verbeteren.

Algemene discussie en aanbevelingen

Palliatieve zorg is anders dan andere gebieden in de gezondheidszorg omdat het een benadering van zorg is die meerdere componenten omvat dan enkel het verlichten van de symptoomlast en die dus rekening houdt met verschillende dimensies van kwaliteit van zorg en leven voor patiënten, maar ook hun familie. Daarom dient een kwaliteitsindicatoren set voor palliatieve zorg deze holistische en mulitidisciplinaire benadering te weerspiegelen zodat de kwaliteit van palliatieve zorg in alle facetten gemeten kan worden. De ontwikkelingsmethode die we gebruikt hebben in het kader van dit doctoraatsonderzoek sluit hier naadloos bij aan. We zijn erin geslaagd een comprehensieve indicatoren set te ontwikkelen die alle domeinen van kwaliteit van palliatieve zorg omvat, die alle perspectieven (zowel van zorgverleners als –gebruikers en beleidsmakers) combineert en die gebruikt kan worden om de zorg te verbeteren voor alle patiënten die gebruik maken van een palliatieve zorgvoorziening. De gestandaardiseerde methode die we ontwikkelden en die bestond uit een literatuurstudie, expert panels, een pilootstudie en voorbereiding op grootschaligere implementatie, kan tevens gebruikt worden in andere landen om kwaliteit van palliatieve zorg te monitoren aan de hand van kwaliteitsindicatoren. Daarbij kan onze kwaliteitsindicatoren set dienen als basis zodat deze indien nodig aangepast, verder gevalideerd en getest kunnen worden voor de palliatieve zorg in dat land. Daarnaast kunnen de indicatoren een basis vormen voor een internationale minimale set om de kwaliteit van palliatieve zorg te monitoren en verbeteren waar nodig.

De kwaliteitsindicatoren set die ontwikkeld werd is in de eerste plaats bedoeld voor *intern* gebruik door de palliatieve zorgvoorzieningen in Vlaanderen. Dit wil zeggen dat de verschillende voorzieningen de indicatoren set herhaaldelijk kunnen meten (2 x per jaar) om de kwaliteit van hun geleverde zorg te evauleren over de tijd en te verbeteren waar nodig. Om de kwaliteitsindicatoren succesvol geïmplementeerd te krijgen in de verschillende zorgvoorzieningen hebben we een implementatieplan ontwikkeld gebaseerd om de geïdentificeerde barrières en facilitatoren. Dit plan omvat onder andere een intensieve training over het gebruik van de kwaliteitsindicatoren om kwaliteit van zorg te meten en verbeteren, het voorzien van alle nodige documenten om de meting uit te voeren (vragenlijsten, brieven, handleiding) en het berekenen van de kwaliteitsindicator scores. Van zodra verschillende palliatieve zorgvoorzieningen de kwaliteitsindicatoren in gebruik nemen volgens het implementatieplan, dient de kwaliteit van het implementatieproces en de kwaliteit van de strategieën geëvalueerd te worden. Aan de hand van zo’n procesevaluatie kunnen tevens bijkomende barrières en facilitatoren geïdentificeerd worden om het gebruik van de indicatoren verder te begeleiden en problemen te anticiperen waar nodig.

Naast intern gebruik, behoort *externe kwaliteitsevaluatie* van de palliatieve zorg op grotere schaal (bv. Vlaanderen) tot de opportuniteiten van de kwaliteitsindicatoren set die ontwikkeld werd. Extern gebruik van de indicatoren, ook evaluatie van de performantie van de palliatieve zorgvoorzieningen genoemd, impliceert dat de indicatoren door verschillende palliatieve zorgvoorzieningen moeten gemeten worden, en dat ze dus toepasbaar moeten zijn voor grote populaties. Daarom is het belangrijk dat alvorens over te gaan tot extern gebruik, een aantal verdere stappen worden ondernomen die ervoor zorgen dat de kwaliteitsindicatoren gebruikt worden voor de juiste doeleinden. Allereerst dienen de kwaliteitsindicatoren verder gevalideerd te worden voor grote populaties palliatieve patiënten in termen van bruikbaarheid, discriminatieve power en haalbaarheid. Daarnaast dienen case mix adjusters of risk adjusters te worden geïdentificeerd: aangezien sommige zorgvoorzieningen soms een ander type van patienten verzorgen en bepaalde kenmerken van die patienten de scores van de kwaliteitsindicatoren sterk kunnen beinvloeden moeten we daarvoor een statistische correctie doorvoeren en aldus een eerlijke vergelijking in kwaliteit van zorg tussen verschillende zorgvoorzieningen mogelijk te maken. Daarnaast dienen beleidsmakers de nodige ruimte en middelen te voorzien binnen de palliatieve zorgvoorzieningen om de kwaliteitsindicatoren op een correcte manier te gebruiken en toe te passen in een algemeen verbeterbeleid binnen de palliatieve zorg.

Kwaliteitsindicatoren zijn pas nuttig en effectief als ze een betekenisvolle kwaliteitsverbetering teweeg kunnen brengen binnen de palliatieve zorg. Op intern niveau, kunnen hulpverleners aan de slag door de kwaliteitsindicatoren in te bedden in een verbetertraject. Op Vlaams (extern) niveau kunnen hiertoe nationale verbetertrajecten uitgezet worden, door de effecten van verbeterprogramma's te gaan meten over de tijd met de kwaliteitsindicatoren.

Tot nu toe is er nog weinig geweten over de invloed die kwaliteitsindicatoren kunnen uitoefenen op de uitkomsten voor patiënten en hun familie. Daarom is er meer onderzoek nodig naar de effecten van het gebruik van kwaliteitsindicatoren op uitkomsten van de zorg. Onze kwaliteitsindicatoren set is een goed startpunt voor zo'n uitgebreide effect analyses.

Appendix I

Minimal quality indicator set for palliative care services in Flanders, Belgium

Legend: Ca = caregivers   Ph = physician Pa = patient   Fc = family carer

1.	**Physical aspects of care**		
		Indicator description	**Measurement question**
1	Ca	Nominator: number of patients who were subjected to a general symptom assessment on a validated scale Denominator: total number of patients for whom this indicator was measured	Have you or any other carer evaluated the patient's symptom burden since the admission or start of palliative care? ☐ Yes, with a scale ☐ Yes, without a scale ☐ No
2	Ph	Nominator: number of patients whose symptom burden was mostly or completely under control in the final week of life Denominator: total number of patients for whom a palliative care service was involved for at least 3 days	Did you have the feeling that the patient's symptom burden (such as pain, anxiety, shortness of breath ...) were under control in the last week before death? ☐ Yes, totally ☐ Yes, largely ☐ No, not totally ☐ No, totally not ☐ I don't know
3	Ca	Nominator: number of patients who were subjected to a pain assessment, with or without pain scale Denominator: total number of patients for whom this indicator was measured	Have you or any other carer measured the patient's pain since the admission or start of palliative care? ☐ Yes,with a pain scale ☐ Yes,without a pain scale ☐ No
4	Pa	Nominator: number of patients who, after treatment, experienced significant improvement in pain Denominator: total number of patients treated for pain	In your opinion, did the treatment adequately relieve the pain? ☐ Yes, ☐ No
5	Ca	Nominator: number of patients whose shortness of breath was relieved within 48 hours after admission or starting palliative care Denominator: total number of patients with shortness of breath	Was the patient suffering from shortness of breath at the time of admission or when palliative care was started? ☐ Yes ☐ No Did you or any other carer take action to relieve this patient's shortness or breath after admission or after starting palliative care? ☐ Yes, ☐ No How long after the patient was admitted or after palliative care was started was a relief of the shortness of breath achieved? ☐ (hours-days) ☐ No relief was achieved

2. Psycho-social aspects of care			
		Indicator description	**Measurement question**
6	Pa	Nominator: number of patients who indicated that the caregivers regularly assessed how they were feeling Denominator: total number of patients for whom this indicator was measured	Have your carers checked how you are feeling? ☐ Yes, regularly ☐ Yes, once ☐ No
7	Fc	Nominator: number of family carers who indicated that the caregivers regularly talked to them about what it meant to them to care for their ill next of kin Denominator: total number of family carers who cared for their ill next of kin	Did the carers talk to you about what it meant to you to care for your sick relative? ☐ Yes, regularly ☐ Yes, once ☐ No
8	Fc	Nominator: number of family carers who indicated that the caregivers regularly asked how they were feeling Denominator: total number of family carers for whom this indicator was measured	Did the carers ask how you were feeling? ☐ Yes, regularly ☐ Yes, a few times ☐ No
9	Fc	Nominator: number of family carers who were given as much assistance as necessary with the care process Denominator: total number of family carers who needed assistance with the care process	Did you feel that the carers gave you all the help and support you needed to care for your relative? ☐ Yes, I received all the help I needed ☐ Yes, I received help but not enough ☐ No, although I tried to get more help ☐ No, but I did not ask for more help either ☐ I did not need any help
10	Pa	Nominator: number of patients with a score of 5 or more on a scale of 0 to 10 for quality of life Denominator: total number of patients for whom this indicator was measured	When you consider all aspects of your life - physical, psychological, social, spiritual, existential and financial - your quality of life over the past 2 days was: (very bad) 0 --------------------- 10 (excellent)
11	Pa	Nominator: number of patients who indicated that the caregivers most of the times or always respected their personal wishes and that they could most of the time or always plan their day and decide about the care provided Denominator: total number of patients for whom this indicator was measured	Do your carers give you the freedom to plan your day? ☐ Never ☐ Sometimes ☐ Usually ☐ Always ☐ Not applicable. Can you co-decide about your care? ☐ Never ☐ Sometimes ☐ Usually Do your carers take your personal wishes into account? ☐ None of them do ☐ Some of them do ☐ Most of them do ☐ All of them do

3. Information, communication and care planning

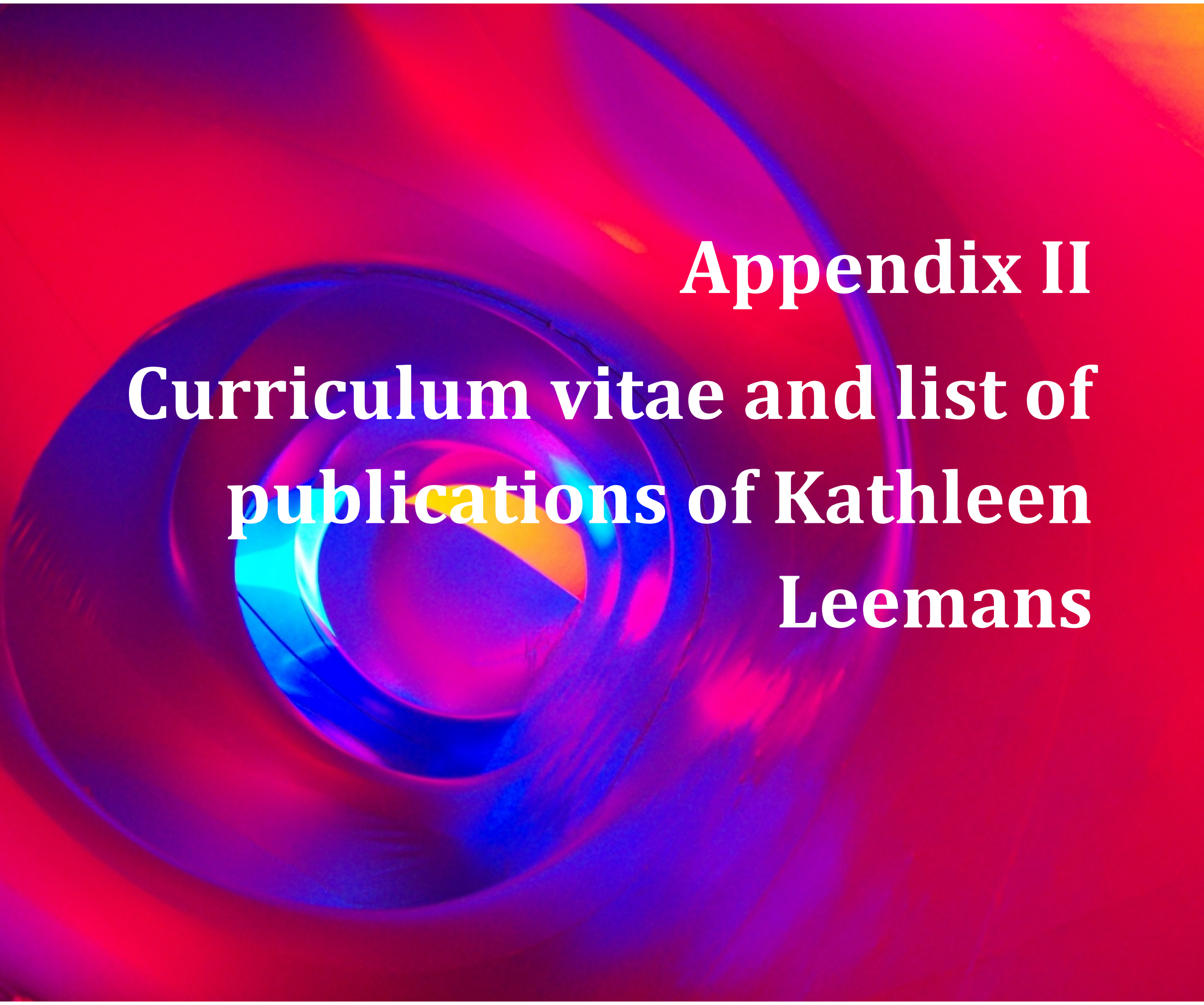
		Indicator description	Measurement question
12	Pa	Nominator: number of patients who received the right amount of information about their diagnosis Denominator: total number of patients for whom this indicator was measured	Are you getting enough information about the following topics? *Diagnosis:* ☐ less than necessary ☐ just the right amount ☐ more than enough
13	Pa	Nominator: number of patients who received the right amount of information about the course of the disease Denominator: total number of patients for whom this indicator was measured	Are you getting enough information about the course of the disease? ☐ less than necessary ☐ just the right amount ☐ more than enough
14	Pa	Nominator: number of patients who received the right amount of information on palliative care options Denominator: total number of patients for whom this indicator was measured	Are you getting enough information with regard to end-of-life care? ☐ less than necessary ☐ just the right amount ☐ more than enough
15	Pa	Nominator: number of patients who indicated that they most of the time or always received clear and comprehensible and never or sometimes contradictory information Denominator: total number of patients for whom this indicator was measured	Do your carers explain things to you understandably? ☐ Never ☐ Sometimes ☐ Usually ☐ Always Do your carers give you conflicting information? ☐ Never ☐ Sometimes ☐ Usually ☐ Always
16	Fc	Nominator: number of family carers who received the right amount of information about the patient's condition and treatments Denominator: total number of family carers for whom this indicator was measured	Did you receive information about your relative's condition? ☐ less than needed ☐ the right amount ☐ more than needed Did you get information about the pros and cons of different treatments? ☐ less than necessary ☐ just the right amount ☐ more than enough
17	Fc	Nominator: number of family carers who received the right amount of information about the patient's approaching death Denominator: total number of family carers for whom this indicator was measured	Did you get information about the impending death? ☐ less than necessary ☐ just the right amount ☐ more than enough

		Indicator description	Measurement question
18	Fc	Nominator: number of family carers who felt they had adequate support after the patient's death (inclusive evaluation meeting) and were informed of the possibilities of after-care. Denominator: total number of family carers for whom this indicator was measured	Did you feel supported by the carers immediately after the death of your relative? ☐ Yes, ☐ No ☐ Not applicable. Was there a farewell- or staff appraisal interview that looked back on the care and treatment that was provided? ☐ Yes, ☐ No Where the possibilities of after-care discussed with you after the death of your relative? ☐ Yes, ☐ No
19	Ca	Nominator: number of patients about whom multidisciplinary consultations took place at least once a week about their care objectives Denominator: total number of patients for whom the palliative care service was involved for at least 1 week	How often, in the past month, was a formal multidisciplinary consultation meeting held for this patient between carers to discuss the care objectives and/or options in terms of palliative care? ☐ once ☐ Less than once a week ☐ Approximately once a week ☐ Almost daily ☐ No formal multidisciplinary meetings have taken place (yet)
20	Ca	Nominator: number of patients about whom a conversation about their care preferences took place between the caregivers and family carers in the first week after admission or start of palliative care Denominator: total number of patients for whom this indicator was measured	How long after admission/hospitalization or after palliative care was started, did the carers/carers meet to discuss the patient's care preferences? ☐ (hours - days) ☐ No conversation has taken place (yet) with the family about the care preferences
21	Ph	Nominator: number of patients with whom the physician discussed the care objectives Denominator: total number of patients for whom this indicator was measured	Have you ever talked to the patient about his or her wishes with regard to the care objectives? ☐ Yes, once ☐ Yes, several times ☐ No ☐ I don't know.

		Indicator description	Measurement question
22	Ph	Nominator: number of patients who were in touch with their family physician on a weekly basis in the last 3 months before death (personally or by telephone) Denominator: total number of patients for whom this indicator was measured	Did you have contact with the patient in the last 3 months of his/her life? ☐ Yes, by telephone ☐ Yes, in person ☐ Yes, both by telephone and in person ☐ No How often did you see or hear from the patient in those last 3 months? ☐ Every day ☐ A few times a week ☐ Every week ☐ Every month ☐ Less than once a month ☐ I don’t know
23	Ca	Nominator: number of patients (or representatives) who were asked how they felt about end of life decisions and euthanasia Denominator: total number of patients for whom this indicator was measured	Have you or another carer inquired about the patient's opinion with regard to end-of-life decisions? ☐ Yes, ☐ No Have you or another carer asked the patient's opinion with regard to euthanasia? ☐ Yes, ☐ No
24	Fc	Nominator: number of patients who got a positive response to (all) their request(s) for a treatment or an end-of-life decision Denominator: number of patients who requested a treatment or an end-of-life decision	Indicate about which of the following treatment decisions your relative asked the doctor or another carer a question. ☐ Discontinuing a life-prolonging treatment ☐ Increasing pain medication with a potentially life-shortening effect ☐ Administering medication with the intention of rendering your relative unconscious (palliative sedation) ☐ Administering life-ending drugs on your relative's own explicit request (euthanasia) ☐ None of the above decisions Did the carers take each of these questions about a treatment decision seriously? ☐ Yes, ☐ No

4. Type of care and circumstances surrounding death			
		Indicator description	**Measurement question**
25	Fc	Nominator: number of patients who scored 5 or more on a scale of 0 – 10 for the quality of death according to family carers Denominator: total number of patients for whom this indicator was measured	Please indicate on a scale from 0 to 10 how you perceived your relative's death? (restless death) 0 ------------10 (peaceful death)
26	Ph	Nominator: number of patients who scored 5 or more on a scale of 0 – 10 for the quality of death according to physicians Denominator: total number of patients for whom this indicator was measured	Please indicate on a scale from 0 to 10 how you perceived the patient's death? (restless death) 0 -------------- 10 (peaceful death)
27	Ph	Nominator: number of patients whose palliative care started at least 2 weeks before death Denominator: total number of patients for whom this indicator was measured	When did you start the palliative care for this patient? ☐ (dd/mm/yyyy) ☐ I don't know. When did this patient start receiving support from the palliative team? *(extra question if a family doctor is completing the questionnaire)* ☐ (dd/mm/yy) ☐ I don't know
28	Ph	Nominator: number of patients admitted more than once to the emergency room since admission or start of palliative care Denominator: total number of patients for whom this indicator was measured	Was this patient admitted to the emergency department more than once since admission or since the start of the palliative care? ☐ Yes ☐ No ☐ I don't know.
29	Ph	Nominator: number of patients admitted to the intensive care unit since admission or start of palliative care Denominator: total number of patients for whom this indicator was measured	Was this patient ever taken to intensive care since admission or since the start of the palliative care? ☐ Yes, ☐ No ☐ I don't know.

5.	Coordination and continuity of care		
		Indicator description	**Measurement question**
30	Ca	Nominator: number of patients whose caregivers were given the care objectives and resuscitation status during or after admission or starting palliative care Denominator: total number of patients for whom this indicator was measured	Did your GP, the physician or other carers inform you of the patient's care objectives? ☐ Yes ☐ No Did your GP, the physician or other carers inform you of the patient's resuscitation status? ☐ Yes ☐ No
31	Ca	Nominator: number of patients for whom the prognosis, psychosocial symptoms, functional status, symptom burden and documentation about care wishes were entered in the file within 48 hours after admission or starting palliative care Denominator: total number of patients for whom this indicator was measured	Which of the following information was noted in the records within 48 hours after admission or starting palliative care? ☐ Patient's prognosis ☐ Patient's psychosocial symptom burden ☐ Patient's functional status ☐ Patient's general symptom impact evaluation ☐ Documentation with regard to the patient's desired care and treatment.



Appendix II

Curriculum vitae and list of publications of Kathleen Leemans

Curriculum vitae of Kathleen Leemans

Kathleen Leemans was born on the third of August 1985 in Duffel, Belgium, as the only child of Bart Leemans and Francine Verlinden.

Kathleen attended secondary school in Regina Pacis Hove, where she graduated in 2003. Afterwards she studied clinical psychology at the Vrije Universiteit Brussel, where she obtained her master degree in 2008.

Shortly after, in February 2009, Kathleen started working as a junior researcher at the End of Life Care Research Group Vrije Universiteit Brussel and Ghent University. During her PhD trajectory she developed quality indicators for palliative care in Flanders, Belgium, supervised by Prof. Luc Deliens and Prof. Joachim Cohen, and co-supervised by Prof. Lieve Van den Block. In the upcoming 2 years she will continue working on a project to implement the quality indicators into the Flemish palliative care services.

Kathleen is married to Kris, mother to Nora and a passionate ballet dancer.

List of publications of Kathleen Leemans

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