Chapter 1
General Introduction
This thesis focuses on quality indicators that can be used to assess and subsequently improve the quality of palliative care, from an international point of view. This introduction will first provide some insights into what palliative care is and how the quality of the palliative care provided can be measured using quality indicators, in order to create a better understanding of this topic before coming to the specific results of the studies presented. This introductory chapter ends with the objectives and main research questions of this thesis, followed by a short description of the methods used to answer these questions.

BACKGROUND

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

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

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

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

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

<table>
<thead>
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<tr>
<td>Effective</td>
<td>Delivering healthcare that is adherent to an evidence base and results in improved health outcomes for individuals and communities, based on need.</td>
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<tr>
<td>Efficient</td>
<td>Delivering healthcare in a manner which maximizes resource use and avoids waste.</td>
</tr>
<tr>
<td>Accessible</td>
<td>Delivering healthcare that is timely, geographically reasonable, and provided in a setting where skills and resources are appropriate to medical need.</td>
</tr>
<tr>
<td>Acceptable/Patientcentered</td>
<td>Delivering healthcare which takes into account the preferences and aspirations of individual service users and the cultures of their communities.</td>
</tr>
<tr>
<td>Equitable</td>
<td>Delivering healthcare which does not vary in quality because of personal characteristics, such as gender, race, ethnicity, geographical location or socioeconomic status.</td>
</tr>
<tr>
<td>Safe</td>
<td>Delivering healthcare which minimizes risks and harm to service users.</td>
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Whereas quality-of-care research in general started in the 1960s and 1970s, research on the quality of palliative care started more recently, and has received increasing attention in the last fifteen years. Researchers and policy-makers have been advocating more research on the quality of palliative care, specifically research aimed at developing and using indicators of good palliative care. One way to make the quality of care transparent, and to evaluate and monitor the quality of care is to use quality indicators.

**Quality indicators**

*Definition and background*

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

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Table 2 – Meaning of structure, process, and outcome of care

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

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

Table 3 provides an overview of the quality indicators that will be explored in this thesis, to give some more concrete examples of quality indicators for palliative care.
supervisory authorities such as the Dutch Health Care Inspectorate.\textsuperscript{18,22,28,33} Indicators have a role in controlling the quality of care when they are used by researchers, managers, patient organizations, and policy-makers. Thirdly, quality improvement, not only for professionals working in a specific care setting, but also for relatives who indicate that their patient died peacefully\textsuperscript{25} and patient-related outcome measures.\textsuperscript{28,35} In addition, quality indicators also have a relationship with measurement instruments (PROMs) that measure their perceptions of their own functional status and wellbeing\textsuperscript{36,37}. These are standardized, validated questionnaires that are completed by patients to illustrate by the quality indicator “the percentage of patients with pain evaluated according to a numeric or other validated pain scale”.\textsuperscript{38}

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

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

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

<table>
<thead>
<tr>
<th>QUALITY INDICATOR</th>
<th>NUMERATOR and DENOMINATOR</th>
<th>TYPE</th>
<th>PERFORMANCE STANDARD</th>
</tr>
</thead>
</table>
| The percentage of patients dying at home\textsuperscript{24} | Numerator: the number of patients dying at home  
Denominator: the total number of patients | Outcome | ≥ 95% |
| The percentage of patients who died in the location of their preference\textsuperscript{25} | Numerator: the number of relatives who indicate that the patient died in the location of his/her preference  
Denominator: the total number of relatives for whom this quality indicator was measured | Outcome | Not specified yet, best-practice norms will be assessed in the future |
| The percentage of time spent in hospital\textsuperscript{24} | Numerator: the number of days in hospital during home palliative care  
Denominator: the total number of days of home palliative care | Outcome | <10% |
| The proportion (of patients) with more than one hospitalization in the last 30 days of life\textsuperscript{26} | Numerator: the number of patients who died from cancer and had more than one hospitalization in the last 30 days of life  
Denominator: the number of patients who died from cancer | Outcome | <4% |
| The percentage of relatives who indicate that the patient died peacefully\textsuperscript{25} | Numerator: the number of relatives who indicate that their relative died peacefully  
Denominator: the total number of relatives for whom this quality indicator was measured | Outcome | Not specified yet, best-practice norms will be assessed in the future |
Standard for Palliative Care (in Dutch: Zorgmodule Palliatieve Zorg), which includes six indicators concerning communication with patients and shared decision making, multidisciplinary care, coordination of care, documentation of a care plan, and after-care for relatives.\textsuperscript{34}

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

**Feasibility of quality indicators**

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

**Quality indicators for palliative care**

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

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

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<th>Quality Indicator</th>
<th>Description</th>
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</tr>
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<tr>
<td>The percentage of patients dying at home</td>
<td>% of patients dying at home</td>
<td>Number of patients dying at home</td>
<td>Total number of patients</td>
</tr>
<tr>
<td>The percentage of relatives who indicate that their relative died peacefully</td>
<td>% of relatives indicating peaceful death</td>
<td>Number of relatives indicating peaceful death</td>
<td>Total number of relatives</td>
</tr>
<tr>
<td>The percentage of patients who died from cancer and had more than one hospitalization in the last 30 days of life</td>
<td>% of patients with multiple hospitalizations</td>
<td>Number of patients with multiple hospitalizations</td>
<td>Total number of patients from cancer deaths</td>
</tr>
<tr>
<td>The percentage of patients who died in the location of their preference</td>
<td>% of patients dying in preferred location</td>
<td>Number of patients dying in preferred location</td>
<td>Total number of patients</td>
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Various domains of palliative care were covered, but indicators covering psychosocial, spiritual, and cultural domains of care were underrepresented. The scientific and methodological rigor regarding the basis and development of these quality indicators varied considerably between indicator sets, and details regarding the development process were often not available.\textsuperscript{15}

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

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

**OBJECTIVES, MAIN RESEARCH QUESTIONS, AND METHODS**

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

The studies described did not focus on collecting new data; instead, they are based on existing datasets and a systematic review to explore the quality of palliative care using quality indicators.
PART 1 – **Existing quality indicators for palliative care**

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

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

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

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

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

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

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

2. Is it feasible to calculate quality indicator scores regarding (a) place of death and (b) hospitalizations at the end of life of home-dwelling patients, on the basis of existing data from general practitioner sentinel networks?

3. Are expected differences in quality indicator scores related to actual differences in the care provided in Belgium, the Netherlands, Italy, and Spain?

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

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

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

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

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

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

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

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

The Dutch DEOLD study\textsuperscript{45,46} describes the quality of dying and satisfaction with end-of-life care and decision-making from the perspectives of family members and elderly care physicians. Nineteen nursing-home organizations participated in this study,
covering a total of 34 long-term care facilities (28 nursing homes and six residential homes). Seventeen participating nursing-home organizations collected data prospectively, meaning that residents were followed from admission to the nursing home until their death or the study conclusion. Two organizations collected data retrospectively (after death) only, to increase the number of reports on decedents while avoiding the complicated logistics involved in prospective studies. Data were collected between January 2007 and July 2010.

Data from the Dutch DEOLD study were used in Chapter 5 to investigate how many residents died peacefully according to their relatives, and whether characteristics of the care provided and of the care facility were associated with the quality indicator scores for dying peacefully, in addition to characteristics of the resident.

The Dying Well with Dementia study is a retrospective cross-sectional study, involving a representative sample of 69 Flemish long-term care facilities. Residents for whom the GP or nurse indicated that the resident "had dementia" or "was diagnosed with dementia" were selected from all the nursing-home residents who died between May and October 2010.

Data from the Dying Well with Dementia study in Flanders are discussed in Chapter 6 to see how many residents died peacefully according to their relatives, and to explore whether dying peacefully is related to physical and psychological distress in residents with dementia.

The general discussion in Chapter 7, the final part of this thesis, will highlight the main findings of Chapters 2 to 6 and interpret these results thoroughly. Furthermore, some methodological considerations will be formulated, as well as implications for research, clinical practice, and policy-making.
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46. van der Steen JT, Ribbe MW, Deliens L, Gutschow G, Onwuteaka-Philipsen BD. Retrospective and prospective data collection compared in the Dutch End Of Life in Dementia (DEOLD) study. Alzheimer Dis Assoc Disord 2014; accepted for publication(28):1-88.