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

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

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

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

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

**Chapter 3** focuses on two indicators concerning the place of death: “the percentage of patients dying at home”\(^1\) and “the percentage of patients who died in the place of their preference”.\(^2\) The indicator scores were calculated for patients mainly residing at home in the last month before death. The percentage of home deaths was 35.3% for Belgium (N=1036), 49.1% for Italy (N=1639), 51.3% for Spain (N=565), and 50.6% for the Netherlands (N=512). None of the four countries reached the performance standard of 95% formulated by the original indicator set,\(^1\) which was developed for palliative home care. However, not all patients in the study population of Chapter 3 received palliative home care. The preferred place of death was known by the GP in 29.7% of patients in Italy, 33.1% in Spain, 42.5% in Belgium, and 60.4% in the Netherlands. Of these patients, 67.8% died at the place of their preference in Italy (N=485), 72.6% in Belgium (N=437), 75.4% in the Netherlands (N=303), and 86.0% in Spain (N=165). So far, no performance standard has been formulated for this indicator, as the developers of this set\(^2\) indicated that a “relative” best practice norm should be derived from the best scoring care providers in practice (e.g. the lower limit of the best scoring quartile of care providers).

Chapter 3 also shows that some care characteristics are related to quality indicators concerning dying at home and at the place of preference (in patients whose preference was known). Patients were more likely to die at home (in all four countries) and more likely to die at their place of preference (significant in Belgium, the Netherlands, and Italy) when the GP provided palliative care. Patients were less likely to die at home (in Belgium and Spain) when cure was still an important care goal in the last two to four weeks of life, and were also less likely to die at home when life prolongation was still an important care goal at that time (in Italy and Spain).
Chapter 4 goes into depth on quality indicators concerning hospitalizations in the last month of life: “the percentage of time spent in hospital”\(^1\) in the last month of life, and “the proportion of patients with more than one hospitalization in the last 30 days of life”.\(^3\) As one of the indicators was originally developed for cancer patients\(^3\) and the other one for home palliative care,\(^1\) only cancer patients mainly residing at home in the last month of life were included. The analyses show that 14.1% of time in the last month of life was spent in hospital in the Netherlands (N=310), 17.7% in Spain (N=224), 22.2% in Italy (N=764), and 24.6% in Belgium (N=500). None of the four countries met the performance standard, which states that less than 4% of patients should be hospitalized more than once in the last month of life. The percentage of patients who were hospitalized more than once in the last month of life was 0.6% in the Netherlands (N=310), 3.1% in Italy (N=764), 4.0% in Spain (N=224), and 5.4% in Belgium (N=500). This means that the Netherlands and Italy meet the performance standard, which states that less than 4% of patients should be hospitalized more than once in the last month of life.

The analyses of Chapter 4 also show that less time was spent in hospital in the last month of life in the Netherlands (N=310) and fewer patients were hospitalized more than once in the last month of life (only significant in Italy) in the group of patients receiving palliative care from their GP compared with patients who did not receive palliative care from their GP. The differences in indicator scores between the four countries seem to reflect specific differences in the organization of care in general and palliative care in particular. One of these differences is the role of the GP. In the Netherlands, for example, GPs have substantial responsibility, both in healthcare in general, where they fulfill a gatekeeper function controlling access to second-line care, and in palliative care. Probably, this is one of the reasons why hospitalizations are shorter and patients are hospitalized less frequently in the Netherlands.

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

In Chapters 5 and 6, the quality indicator “the percentage of relatives who indicate that the patient died peacefully”\(^2\) was explored with the help of two datasets. Chapter 5 is based on data from the “Dutch End of Life in Dementia” study, a study concerning care at the end of life for residents with dementia (N=233) in 28 nursing homes and
four care homes in the Netherlands. Chapter 6 worked with data from the “Dying Well with Dementia in Flanders” study, which took place in 69 nursing homes in Flanders (Belgium) and concerned deceased residents with dementia (N=92). Quality indicator scores found in the two chapters are comparable: in the Netherlands, 56.2% of the relatives indicated that the resident died peacefully (Chapter 5), while the percentage in Flanders was 54.4% (Chapter 6). The data for the Netherlands were also investigated to see how this indicator score differed between different care facilities. Quality indicator scores varied between 17% and 80%, with most care facilities having a score between 30% and 64% (Chapter 5).

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

The last chapter (Chapter 7) summarizes the most important results of the previous chapters and reflects on the findings and methodological aspects in a broader context, resulting in some recommendations. In brief, these recommendations include the following. Since a lot of quality indicators for palliative care have already been developed, it is recommended to use and further develop these existing quality indicators in clinical practice and quality research. Ideally, these indicators should be tested further in practice and adjusted where needed, and be optimized in this way. Furthermore, international organizations should promote the use of quality indicators and the definition of an international minimum set of quality indicators. Using this minimum indicator set on a national and international level could contribute to the transparency of the quality of palliative care. In addition, policy-makers and researchers need to investigate ways to calculate quality indicator scores with routinely collected data. This dissertation has shown that data collected by GP sentinel networks can be used to calculate quality indicator scores.
Last but not least, it is important for policy-makers and researchers to realize that measuring quality indicator scores is just a first step toward actually improving the quality of care. Caregivers can use quality indicators scores to verify which aspects of care could be enhanced. Ideally, this should lead to strategies to improve this suboptimal quality of care.

REFERENCES

