Chapter 7

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

**MAIN FINDINGS**

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

The international systematic review (Chapter 2) was performed to get insight into the kind of quality indicators for palliative care that have been developed so far. This review identified a substantial number of relevant indicators (17 sets of quality indicators, 326 unique quality indicators). The quality indicators mostly focus on care for specific patient populations, e.g. cancer populations or the vulnerable elderly, and on specific care settings, e.g. hospice care or palliative care in the intensive care unit. Physical aspects of care and the structure and process of care (e.g. covering communication with patients and family) received most attention in the existing quality indicators, whereas domains concerning social, spiritual, and cultural aspects of care were covered less.

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

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

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

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

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

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

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

We also investigated the feasibility of measuring these quality indicators based on data gathered by the GP sentinel networks. The quality indicator scores regarding home deaths, frequency of hospitalizations in the last month of life, and duration of hospitalizations in the last month of life could be calculated from the data from the GP sentinel networks, since the number of missing values was low. On the other hand, the quality indicator describing whether patients died at their location of preference had a high proportion of missing values, since GPs only knew where their patient wanted to die in 30-60% of cases, showing that exploring patient’s preferences may be a challenging process.
Quality indicators should reflect the quality of care provided rather than patient characteristics. We therefore also investigated whether expected differences in quality indicator scores are related to actual differences in the care provided or the organization of care in Belgium, the Netherlands, Italy, and Spain. Receiving palliative care from the GP was positively associated with both dying at home in a population of home-dwelling patients who died non-suddenly in all four countries, and with dying at the location of preference in Belgium, the Netherlands, and Italy. Some care goals in the last 2-4 weeks of life were significantly associated with dying at home. If cure was an important care goal in the last weeks of life, people were less likely to die at home (significant association in Belgium and Spain). In addition, if prolonging life was an important goal in the last weeks of life, people were less likely to die at home (significant association in Italy and Spain).

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

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

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

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

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

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

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

REFLECTIONS ON THE MAIN FINDINGS

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

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

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

The structure, processes, and outcomes of care were addressed in the indicators found by the systematic review, although processes and outcomes received more attention than the structure of care. All types of indicators have advantages and disadvantages, leading to the suggestion by many authors that a quality indicator set that is broad and comprehensive should include structure, process and outcome indicators. Some authors suggested that it might be easier and cheaper to derive quality indicators concerning processes and structure of care from existing data such as medical records and administrative data or data that is routinely collected. However, this thesis has shown that the five outcome indicators we studied could also be derived from existing data that was not collected primarily with a view to measuring quality. Outcome indicators based on the patient’s and family’s perspective can be an extra burden on patients and family members because of the need to collect data from them, but have the advantage of providing information from their perspective, which is an important component in the assessment of the quality of palliative care. One Dutch quality indicator set, of which we used two indicators in this thesis, focuses primarily on outcomes because the developers felt this should be the main focus of assessment, whereas it is the responsibility of care providers themselves to organize the structures and processes of care in such a way that the desirable outcomes are achieved. However, particularly when poor outcomes are measured, it is an advantage if information about processes and structures that are linked to this outcome is available as well, so that this information can be used to improve practice. Therefore, if processes and structures are measured along with outcome indicators, targeted improvement measures can be taken in order to achieve better outcomes.
Differences in quality indicator scores between countries are related to differences in care and policy

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

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

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

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

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

REFLECTIONS ON THE RESEARCH METHODS

Methodological reflections about the systematic review (Chapter 2)

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

Since the publishing process of systematic reviews in peer-reviewed journals takes time, it might be that new evidence has been published in the meantime, making the systematic review no longer completely up to date. Another frequently mentioned limitation of most systematic reviews is that they are performed using international databases that mainly contain scientific peer-reviewed literature and the reviews therefore could miss some of the ‘gray’ literature. We cannot exclude this possibility, but since we found some gray literature when manually checking the references of the articles included, we expect to have kept the number of relevant articles that have been missed to a minimum.
Methodological reflections about the studies presented in Part 2 and 3 (Chapters 3-6)

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

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

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

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

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

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

REFLECTIONS ON THE METHODOLOGICAL PROPERTIES OF QUALITY INDICATORS

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

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

The performance standards defined for quality indicators are often not realistic

The four countries we studied (Chapter 3 and 4) often did not meet the performance standards defined by the original developers of the indicator sets described in our systematic review. In general, fully meeting a performance standard may not be feasible, since palliative care is a complex form of care that should be tailored to the patient’s needs and therefore there will always be exceptions in individual cases even when the best care is provided. Defining a performance standard is a complex issue.\textsuperscript{30}

Performance standards can be perceived in several ways: 1) as a basic level of quality, which ideally all settings or countries should achieve; 2) as a higher quality level, a level that should be reached if the improvement strategies work; 3) as an innovative level, that might not seem achievable at present, but that could become the optimal level in the future.\textsuperscript{53} Striving to meet this innovative quality level should be the aim in the long term, but more feasible performance standards are needed in the meantime. In this regard, it may be a good thing to use best-practice norms as performance standards rather than absolute norms. Absolute norms are often defined by experts, while best-practice norms are derived from the scores of the lower limit of the upper quartile of care providers, for instance. The fact that best-practice norms are derived from scores in actual practice makes them realistic and motivates healthcare professionals to assess and improve quality.

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

Quality indicators were originally developed for comparisons or monitoring at the level of care organizations rather than for cross-country comparisons. Whether one performance standard fits different countries is open to question. For some types of quality indicators, for instance those addressing pain relief, one could argue that people should receive optimal pain relief regardless of the country where they are cared for, and thus one performance standard could be defined for all countries. However, for quality indicators directly related to national healthcare policies, e.g. quality indicators on hospitalizations or place of death, one could argue that defining a performance standard at a national level could be more appropriate.
Chapter 7

IMPLICATIONS FOR RESEARCH

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

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

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

Development process of quality indicators should be described in detail

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

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

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

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

Existing quality indicators should be further tested and used in practice

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

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

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

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

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

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

**IMPLICATIONS FOR POLICY AND PRACTICE**

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

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

Secondly, these international organizations should encourage data collection for this minimum quality indicator set on a national level and facilitate the sharing and distribution of these data. These national quality indicator scores should be made transparent, for instance in annual reports by these organizations, or in reports on the development of palliative care, for instance the Palliative Care Atlas by the European
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In addition, cross-country comparisons of the quality indicator scores for the minimum indicator set should also be used by international organizations to establish realistic performance standards for countries based on best-practice norms. Policymakers from a country with suboptimal performance could be inspired by policies of other countries that score better on certain quality indicators and could consequently change or adapt their own policies. In this regard, it is worth mentioning that the appropriateness of one performance standard for different countries could be questioned for some aspects of care. Depending on the aspect of care studied, national governments should define or adapt performance standards according to the priority they give this aspect in their national policies and according to their best practices.

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

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

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

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

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

**CLOSING REMARKS**

This thesis focused on quality indicators that can be used to assess and subsequently improve the quality of palliative care, from an international point of view. We were able to derive quality indicators from existing datasets collected for other purposes and to use these indicators in cross-country comparisons. We used these findings to formulate recommendations for future research, clinical practice, and international and national policy-makers. We hope that this thesis can be a source of inspiration, leading to new opportunities to achieve lasting, wide-spread research on quality and improvements in palliative care.
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Chapter 7


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