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## **New Developments in Palliative Care:**

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*General Discussion*

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This thesis addresses two salient topics in palliative care today: firstly, the development of quality indicators and secondly, the increasing awareness that patients and their families could benefit from palliative care throughout the entire care continuum that starts early in the course of the disease and ends with the patient's death and subsequent aftercare for relatives.

The first part of this thesis describes research on the development of quality indicators. Measuring and reporting quality indicators makes the quality of care transparent for patients and other stakeholders, and can give guidance for quality improvements. The increasing attention being given to the quality of palliative care can be seen both nationally and internationally. The Council of Europe stated in 2003 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".

In 2009, the Council of Europe reconfirmed this point of view and advocated the identification of practical indicators that can be used to check what progress has been made in patient care over a given period. In addition, the Dutch Ministry of Health, Welfare and Sports promotes transparency in the quality of care as well as the use of quality indicators, not only in palliative care but also in other care domains, such as long-term residential care and curative hospital care.<sup>1,2</sup>

The second part of the thesis describes research on the palliative care continuum, the so called 'model of palliative care'. This model is not a theoretical model involving theoretical concepts and relations, but rather a schematic representation of palliative care as a care continuum. This 'model' of palliative care was introduced by Joanne Lynn and David Adamson in 2003<sup>3</sup>, and currently serves as inspiration for researchers, policymakers and professionals in the field of palliative care.<sup>4-6</sup> As said, according to this model, the palliative care continuum starts early in the course of a chronic disease and initially curative treatments may be given alongside palliative treatments. The emphasis on curative treatments decreases gradually, shifting to an emphasis on palliation.<sup>3</sup>

## Key findings and interpretation of the results

The key findings are presented and discussed chronologically, following the two parts of this thesis, on the development of quality indicators (Part 1) and the palliative care continuum (Part 2).

### ***PART 1: The development of quality indicators (Chapters 2, 3 and 4)***

#### *Quality indicators*

A main research question addressed in Chapter 2 of this thesis is:

*What quality indicators are suitable for measuring the quality of palliative care in various settings?*

Thirty-three quality indicators for patients and ten quality indicators for relatives were developed and were found to be suitable for measuring the quality of palliative care in various settings. The set of quality indicators addresses all aspects of palliative care: physical, psychosocial and spiritual care, including the support for relatives. The quality indicators we developed can be of benefit to several parties, e.g. healthcare professionals who want to gain insight in the quality of care within their own organisation, researchers who are interested in quality indicators, and policymakers or healthcare insurers who are interested in the quality of palliative care.

Quality indicators are defined as “measurable aspects which give an indication of the quality of care, and which concern the structures, processes or outcomes of care”.<sup>7</sup>

The quality of care can be made transparent by reporting on the scores achieved by care organisations or care providers for different quality indicators in research reports, policy papers, public websites et cetera. The 43 quality indicators developed in the study presented in Chapter 2 can be subdivided into two main categories: firstly, indicators concerning the subjective care experiences of patients or relatives and secondly, indicators concerning the prevalence of symptoms in patients.

The large majority of these 43 quality indicators are outcome indicators rather than structure or process indicators. Outcome indicators measure the outcomes of care for care users. The decision to focus primarily on outcome indicators was made in accordance with the Dutch government's views on the responsibilities of care organisations: the government considers it the

responsibility of care organisations themselves to set up their structure and care processes in such a way that they lead to desirable outcomes in care users. Some examples of the outcome indicators that have been developed are: 'the percentage of patients with moderate to severe pain' and 'the extent to which patients indicate that caregivers respect their life stance'.

It could be argued that relevant quality information is missed if only outcome indicators are measured. If process indicators and structure indicators were measured as well, it would be easier to assess which care processes or structures have to be changed in order to achieve better outcomes. However, the new set had to be relatively short because of the vulnerability of the care recipients and because of the fact that the care professionals involved in the measurements dislike long, time-consuming instruments. This also prompted the decision to focus mainly on outcome indicators. In addition, it is important to bear in mind that these quality indicators have a 'signalling' function; they do not give a full representation of the quality of palliative care. If the outcome indicators point towards poor quality, this should lead to discussions of the results among the healthcare professionals involved and could also lead to further investigations that take into account the processes and organisational structures as well.

Besides the focus on outcome indicators, another distinguishing feature of the set of quality indicators is that it addresses all domains of palliative care. Psychosocial and spiritual care aspects were under-represented among quality indicators that had previously been developed for palliative care, according to an international, systematic review.<sup>8</sup> This set seeks to fill that gap. The domains of physical and psychosocial care are well covered. Although it turned out to be difficult to develop usable quality indicators for the spiritual care domain, the set also contains some outcome indicators for spiritual care, such as the 'percentage of relatives who indicate that the patient died peacefully'.

Another distinguishing feature of the quality indicator set is the focus on the perspectives of both patients and relatives. A literature review by Ostgathe and Voltz presented an overview of progress in quality indicators for end-of-life care; they looked at definitions, domains and quality indicators.<sup>9</sup> They concluded that closer attention should be given to the insights of patients and family members on what they perceive as quality. Patients' and relatives'

perspectives reflect the essential elements and standards for the best quality of care. This set does justice to the perspectives of patients and relatives on the quality of palliative care, which is far from standard practice internationally. In 2010 the Economist Intelligence Unit published a report on the quality of end-of-life care in 40 countries.<sup>10</sup> According to this report, the Netherlands is ranked among the top 10 countries with the highest quality scores. However, these quality scores mainly concerned the organisational conditions for palliative care, while the perspectives of patients and relatives were disregarded in these quality indicators. The new set of quality indicators presented in this thesis therefore has additional value.

*The CQ-index PC: a tool for measuring quality indicators from a user perspective.*

The following overall research question is addressed in Chapters 3 and 4:

*How can the quality of palliative care be measured from the perspectives of patients and bereaved relatives by using a CQ-index Palliative Care?*

The Consumer Quality Index Palliative Care (CQ-index PC) was developed for measuring quality indicators from the perspectives of patients (see Chapter 3) and bereaved relatives (see Chapter 4) in different care settings.

The patients' version of the CQ-index PC includes questions about care for physical wellbeing, psychosocial wellbeing and spiritual wellbeing, respect for independence, privacy, information and the expertise of caregivers. The relatives' version of the CQ-index PC includes questions about care for the psychosocial/spiritual wellbeing of the patient, care for the relative's own psychosocial/spiritual wellbeing, attitude to the relative, autonomy, information for the relative in the last week before death, and expertise.

The CQ-index PC differs from quality instruments developed in the past, which ask about satisfaction with palliative care – often in a traditional, direct way.<sup>11-16</sup> Moreover, existing instruments often focus on very specific target groups, for example relatives of patients in the final stage of dementia<sup>16</sup>, persons involved in palliative cancer care<sup>17</sup> or persons in a hospice setting.<sup>18</sup> Thus the need for a valid questionnaire to assess the quality of palliative care in various settings prompted the decision to develop a CQ-index for palliative care.

CQ-index questionnaires belong to a new generation of quality questionnaires reflecting the user perspective. The structure of CQ-index questionnaires is largely based on the American CAHPS (Consumer Assessment of Healthcare Providers and Systems).<sup>19</sup> The CAHPS was introduced in 1995 because healthcare insurers in the US wanted comparative quality information to compare providers. In addition, the structure of CQ-indices is largely inspired by the Dutch QUOTE (QUality Of care Through the patient's Eyes) instruments that were introduced in the 1990s after discussions about the conceptual and methodological problems of traditional patient satisfaction surveys.<sup>20</sup> Nowadays, the Dutch Ministry of Health, Welfare and Sport, the Health Care Inspectorate and many healthcare insurers in the Netherlands consider the CQ-index to be the preferred approach for assessing the quality of care from a user perspective. Today, about 30 CQ-indices have been developed<sup>21</sup>, often focusing on a specific care setting (e.g. hospital care or long-term care) or a specific patient group (e.g. patients with rheumatoid arthritis, with breast cancer or congestive heart failure). The CQ-index PC differs from most other CQ-indices because the instrument can be used in various care settings and in patients with different diagnoses. This is related to the fact that palliative care is multidisciplinary care, often involving multiple care providers and not focusing exclusively on one diagnosis group. Hence, the CQ-index PC gives an indication of the quality of the 'total package' of multidisciplinary palliative care rather than the quality of care provided by one specific care provider or organisation.

## ***PART 2: the palliative care continuum and GPs' experiences and perspectives (Chapters 5, 6 and 7)***

### *Recognition of a need for palliative care*

A qualitative interview study with 20 Dutch GPs explored how GPs identify the start of the palliative care continuum, in other words how they identify a need for palliative care in patients. The following overall research questions address this issue (discussed in Chapter 5):

*When and how do GPs recognise a need for palliative care?*

*Are there any differences between patients dying from cancer and patients dying from non-cancer diseases with regard to this issue?*

It was found that GPs often recognise a need for palliative care on the basis of a combination of various, often subtle, signals: signals from the patient – such as increasing care dependency and no recovery after intercurrent diseases – as well as signals from family members or reports from medical specialists. Still, there were some general differences between patient groups in the GPs' identification of a need for palliative care. It is often relatively clear when the palliative phase starts in patients with cancer. In contrast, GPs' awareness of the patient's palliative care needs in the case of chronic patients with COPD or heart failure, for example, or in the frail elderly, often arises more gradually and relatively late in the disease trajectory.

In addition, the interview study also made clear that GPs do not support the idea that palliative care should always start early in the disease trajectory. It makes no sense for them to speak about 'palliative care' when cure is still an option or when the patient does not need much care. Nevertheless, they also give emotional support at the time of the diagnosis of a life-threatening disease. This is consistent with the idea behind the palliative care continuum – that palliative care has to start early – but not with the terminology. GPs hardly use the term 'palliative care' in their communication with their patients because this has no added value for them and the term may be disturbing for patients.

Nevertheless, patients can benefit from an early start to palliative care. Early recognition of a need for palliative care makes advance care planning possible and may therefore prevent crises and unnecessary transitions from one care setting to another.<sup>22</sup> In addition, if patients' palliative care needs are recognised in good time, the care is more likely to be tailored to the specific needs of patients, resulting in better quality of care. There are also indications from a study by Temel et al., performed in a hospital setting, that initiation of palliative care in an early phase of the disease trajectory may result in better patient outcomes.<sup>23</sup> Temel et al. showed that early initiation of palliative care among patients with metastatic non-small-cell lung cancer resulted in significant improvements in the quality of life, mood and median survival time.

### *Co-existence of treatment aims*

The following research questions were addressed (Chapter 6) in a retrospective registration study among a representative Sentinel Network of GPs:

*What are the important treatment aims in the last three months of life for patients with a non-sudden death?*

*Are there any differences between GPs' patients dying from cancer and GPs' patients dying from non-cancer diseases with regard to this issue?*

It was found that for almost all patients (95%) with a non-sudden death, palliation was an important treatment aim in the last week of life, although 7% were still receiving treatments aimed at cure in this last week. These patients mainly had a respiratory or cardiovascular disease. The course of the disease in patients with non-cancer illnesses, such as end-stage COPD or heart failure, may be relatively difficult to predict<sup>24-26</sup>, which may explain why curative treatments are still being given shortly before death.

In addition, the results of this registration study showed that in the last week of life and in the two to four weeks before death, cure was more frequently reported as an important treatment aim for patients with a non-cancer disease than for patients with cancer. Two to four weeks before death, palliation was more often already an important treatment aim for patients with cancer than for patients with other diseases. We also found that palliation and cure/life prolongation were simultaneously important treatment aims in months two and three before death for only 17% of the patients. Hence, only a relatively small proportion of the patients were receiving palliative care alongside curative or life-prolonging care. In this respect, actual practice is not yet consistent with the idea behind the palliative care continuum that different treatment aims go alongside until late in the disease trajectory.

### *When the diagnosis of the disease that ultimately led to death was made and recognition of imminent death*

In an additional study, around 300 Dutch GPs completed a survey questionnaire on when the diagnosis of the disease that ultimately led to death was made and on the recognition of imminent death. The survey

questions concerned the GP's last patient who died non-suddenly. The associated research questions (in Chapter 7) were:

*How long before death is the diagnosis of the disease that ultimately led to death made?*

*On the basis of what kind of information sources do GPs become aware of the diagnosis of the disease that ultimately led to death?*

*How long before their patients' death do GPs recognise that death is imminent?*

*On the basis of what kind of information sources do GPs recognise that death is imminent?*

*Are there any differences between patients dying from cancer and patients dying from non-cancer diseases with regard to these issues?*

The survey showed that the diagnosis was often made very late in the disease trajectory. of non-cancer patients: the diagnosis was not made until the last week of life in 15% of the non-cancer group as opposed to 1% of the patients with cancer. In addition, it was found that imminent death was sometimes only recognised very shortly before death. The GP became aware that death was imminent only in the last week of the patient's life in 6% of the cancer group and 26% of the non-cancer group.

Hence, the diagnosis of the disease that ultimately led to death is made only late in the disease trajectory relatively often, particularly among patients where the cause of death is not cancer. That the diagnosis was not made until the very last week in 15% of the non-cancer group suggests that palliative care for these patients is started only very shortly before death. In this regard, actual practice contrasts with the early initiation of palliative care as proposed by Lynn and Adamson's model.<sup>3</sup>

## **Methodological considerations**

### ***Methodological considerations regarding PART 1: the development of quality indicators***

So far there is no gold standard for the development of quality indicators. We opted for an intensive development process in several phases, in which multiple parties were involved, in order to maximise the likelihood of coming up with a valid and usable set of indicators. The development process consisted of a literature study, consultations with experts, interviews with

patients and bereaved relatives and the testing of a draft set of indicators in practice. All these phases provided input for the development of the final set of quality indicators.

One limitation is that a convenience sample of 14 care organisations from the researchers' own networks was used to test the set for usability. The fact that the sample was non-random may have biased the results, in the sense that these organisations might be expected to be 'forerunners' that are not entirely representative of the average healthcare provider giving palliative care.

Another limitation is that there is no information yet on the discriminative power of the quality indicators and the CQ-index PC, and we therefore do not know whether valid comparisons can be made between the scores of different care providers or between different measurements over time of the same care provider. More research is needed based on data sets from larger samples to establish this.

Like other CQ-indices (e.g.<sup>27-29</sup>), the CQ-index PC assesses actual care experiences and how important the care recipient finds certain care aspects. This is an important difference with traditional satisfaction questionnaires, which ask care users directly about their satisfaction. Asking about actual care experiences – as CQ-indices do – reduces the risk of socially desirable answers.<sup>30,31</sup> Besides, another advantage of CQ-indices is that they provide insight into the priorities for quality improvement as deduced from 'need for improvement' scores (these scores can be calculated by combining the scores of the question about the importance of a care aspect with the scores of the question about experience with this care aspect). This advantage is particularly important for healthcare providers who are planning to initiate quality improvement projects within their care organisation or team.

### ***Methodological considerations regarding PART 2: the palliative care continuum***

The second part of this thesis is based on three sub-studies: a qualitative interview study among GPs, a retrospective registration study among a Sentinel Network of GPs and a survey study among GPs.

A common strength of the three different studies is that all the studies include data about patients with cancer as well as about patients with other chronic diseases (such as COPD or heart failure) and the frail elderly. Previous studies on palliative care have mainly focused on patients with cancer, although it has been recognised that palliative care should be provided on the basis of needs rather than prognosis or diagnosis.<sup>32</sup>

An advantage of the qualitative interview study is that it enabled the subjective experiences and perspectives of GPs to be explored in detail. Qualitative interviews provide 'rich', internally valid data. Qualitative research methods are particularly appropriate when personal experiences and perspectives have to be explored and when research topics are relatively unexplored and no structured measurement instruments are available, as was the case in this sub-study. However, qualitative designs have limitations regarding generalisability and the external validity of the findings, in part because the samples are often small and non-random.

Nevertheless, several measures were taken to enhance the scientific rigour of the research. For example, variation in the sample was ensured by selecting GPs with varying background characteristics (e.g. with different ages and numbers of working hours and from different regions), which contributed to the validity of the results. In addition, the principle of 'data saturation' was used, in the sense that we stopped conducting interviews when it became clear that additional interviews were not resulting in new relevant results. In addition, procedures to enhance the quality of the analyses were used, such as independent, comparative analyses of interviews by a second researcher. Furthermore, 'member checking'<sup>33</sup> was performed by asking for feedback on the analysis from one of the interviewed GPs. Moreover, 'peer debriefing'<sup>33</sup> was carried out by discussing analyses with fellow researchers with different backgrounds. All these measures helped improve the quality and rigour of the research.

A major strength of the registration study is the use of registration data from a large, national Sentinel Network of GPs.<sup>22, 34-38</sup> The Sentinel Network is representative in terms of the age and gender of the GPs and the population density of the areas covered by the general practices.<sup>39</sup> The fact that the GPs in this study participate in an existing Sentinel Network that is used for measuring all kind of interventions and issues in Dutch general practices

reduces the chance of selection bias: the GPs who provided registration data will not have had a special interest in palliative care. On the other hand, there is a risk of recall bias because of the retrospective design in which GPs were requested to provide information on the care deceased patients had received in the last three months of life.

The net response rate for the GPs' questionnaire was not high (36%), although this response was comparable with other recent surveys among Dutch GPs.<sup>40-41</sup> It is known that Dutch GPs have a heavy workload<sup>42</sup>, which may explain why the non-response in this group is often high. It is possible that GPs with a specific interest in palliative care were more likely to respond.

Another characteristic of this study is that GPs had to select their last patient who died non-suddenly. There were a relatively large number of cancer patients among the patients the GPs selected. Van der Velden reported in a death certificate study that every year about 77,000 people die from a chronic disease in the Netherlands. More than half of them, 40,000 (52%), die from cancer.<sup>43</sup> In our study, 76% of the patients selected by the GPs were cancer patients and 24% were non-cancer patients who died non-suddenly. It would seem that GPs associate a non-sudden death more with cancer rather than a non-cancer disease. The relatively low percentage of patients with a stroke (1%) or dementia (6%) is particularly striking. A possible explanation for this might be that these patients often die in nursing homes and the nursing-home physician, rather than the GP, is responsible for the medical care of patients in a nursing home.

## **Policy and practice recommendations**

### ***Policy and practice recommendations regarding the quality indicators***

The quality indicators for palliative care can be used by healthcare providers who want to gain insight into the quality of care within their own organisation (internal use of the set). If an increasing number of palliative-care organisations start using the set of indicators in the future, this would have several advantages. First, the quality indicator set can be tested further for usability and feasibility. The quality indicator set and the measurement procedures can continuously be improved on the basis of user experiences. Besides, future large-scale use would make it possible to obtain a more complete impression of the quality of palliative care in various settings.

The set may also be suitable for quality comparisons between care organisations. Transparent comparative quality information may be relevant for healthcare users who want to choose the best care provider and may also be useful to the Health Care Inspectorate, for instance, or healthcare insurers. At the moment, however, more information is needed on whether valid comparisons can be made with this set of indicators. Therefore more insight is needed into the discriminative power of the quality indicators (see the section on plans and recommendations for future research). In addition, stakeholders, such as representatives of the Ministry of Health, patient organisations and umbrella organisations in the field of palliative care, should discuss to what extent and in what ways comparative quality scores should be made transparent (e.g. in public reports or on websites). In these discussions, due allowance must be made for the fact that facilities in palliative care – such as hospices – are often on a small scale. Valid comparisons can only be made when palliative care providers have a substantial number of patients (preferably more than 20 for a given measurement period).

An important development that may have consequences for the future use of the set of indicators concerns the national standard for palliative care. This standard is currently being developed<sup>44–45</sup> on instigation of the Dutch government and in collaboration with relevant stakeholders. A national standard describes the norms and indicators for good care, which should be implemented on a national level.<sup>46</sup> It is recommended that a selection of the new set of quality indicators for palliative care should be linked to the national standard of palliative care. This will provide opportunities for collecting representative, comparative quality information that may be relevant for patients and relatives, as well as for external parties like the Health Care Inspectorate. In addition, it is expected that in the future healthcare insurers may use this information when negotiating with healthcare organisations about the financing for palliative care.

A related recent development is the development and introduction in 2012 of ‘diagnosis treatment combinations towards transparency’ (‘DOT’). In the Netherlands, a healthcare provider in a hospital receives funding on the basis of ‘diagnosis treatment combination care products’ (DBC care product). A DOT for palliative care has also recently been developed and introduced. One of the prerequisites for declaration of this DOT for palliative care is the

availability of multidisciplinary consultation. If this is lacking in a hospital, palliative care cannot be financed by healthcare insurers. It is likely that in the future additional quality indicators for palliative care – incorporated in the national standard for palliative care – will be a prerequisite for financing the DOT Palliative Care. It is recommended that in addition to objective quality indicators, quality indicators measuring the care users' perspective on the quality of palliative care should also be included.

If stakeholders should decide that the quality indicators have to be introduced on a national scale, much could be learned from previous experience with the national implementation of other quality indicator sets. In the Netherlands, it is the sector for long-term residential and home care that probably has the most profound long-term experience with the measurement of quality indicators. In this sector a mandatory national set of quality indicators<sup>1</sup> has been used for about five years to provide quality information for annual reports and quality improvements by care providers and also for public comparative information (see [www.kiesbeter.nl](http://www.kiesbeter.nl), in Dutch). Like the set of quality indicators for palliative care, two types of quality indicators are involved, namely indicators concerning subjective care experiences and objective care-related indicators. However, these quality indicators have a general character and do not focus on palliative care patients. Patients receiving palliative care form a large group in long-term residential and home care. Therefore, the quality indicators for palliative care and the CQ-index PC can be of additional value to this sector as well.

It is important, both now and in the future, that the measurements of the quality indicators are not too time-consuming and are in line with the available financial and staffing resources of care organisations. One option may be to measure a selection of the quality indicators. It is recommended that as a minimum the quality indicators regarding aftercare are measured because this study suggests that aftercare should be a high priority for quality improvement.

### ***Policy and practice recommendations regarding the palliative care continuum***

The interview study indicated that GPs prefer to avoid the term 'palliative' as long as they have not received signals from the patient that he/she is in need of palliative care or if curative treatments are still possible. Nevertheless, GPs

often give emotional support even in the early stage of the disease trajectory, when the patient has just heard the life-threatening diagnosis. It is recommended that discussions should be initiated on the use of the term 'palliative' or options for alternative terms, for instance in the training and education of healthcare professionals. The education and training of GPs could also include further discussion of what attitude GPs should take in palliative care. It is known from other recent research that Dutch GPs in general have a reactive rather than a proactive attitude in the interaction with their patients<sup>47</sup>, since GPs assume that the patient should say what kind of support they want from the GP and what kind of problems they have. GPs do not want to patronise their patients or give care that is not needed. However, a more proactive approach, e.g. with the GP taking initiatives for advance care planning, may result in a better match with patients' and family members' existing and evolving care needs.

The registration study on treatment aims in the last three months of life established that in the last week before death 7% of the patients were still receiving treatment aimed at cure. It could be argued that these patients are being 'over-treated' in a curative sense. The issue of over-treatment at the end of life is currently receiving a lot of interest in the public media and is also high on the agenda of professional organisations like the Royal Dutch Medical Association (KNMG). Recently, this organisation has published a brochure 'Spreek op tijd over uw levenseinde [talking about the end of life in good time]' in which a plea is made for advance care planning, in the sense of open and timely communication with patients about care needs and preferences. However, it is important that communication styles are adjusted for each patient in each consultation. Some patients – e.g. immigrant patients with a non-Western background – are not used to direct, open communication about the end of life and may have other communication styles (e.g. communication within a triad of care provider – patient – family representative) that need to be respected.<sup>48</sup>

Adequate communication between different healthcare professionals about the coordination of curative, life-prolonging and/or palliative treatments is also essential. Lynn and Adamson's model displaying a care continuum, in which palliative care can coexist with curative and life-prolonging treatments, can make healthcare professionals aware that communication about and the coordination of different treatments are essential. Lynn and

Adamson's model can therefore be helpful in professional training and education about the essence of palliative care.

In the survey study among GPs it was found that for non-cancer patients in particular the diagnosis of the disease that ultimately led to death and imminent death are often recognised relatively late in the disease trajectory. Patients with diseases like COPD or heart failure, or the frail elderly, may therefore not receive timely palliative care. It is recommended that ample attention be given to the recognition of palliative care needs in these groups of patients in the training of doctors, nurses and other relevant healthcare professionals.

## **Plans and recommendations for future research**

### ***Plans and recommendations regarding research on the quality indicators***

The quality indicators for palliative care were tested for usability and feasibility in a convenient sample of 14 care organisations. Further research in a larger sample will provide additional insights into usability and feasibility. A relevant consideration in this regard is that the set of indicators will also be used as an evaluation instrument within the recently started Dutch national palliative care quality programme (see [www.zonmw.nl](http://www.zonmw.nl), in Dutch). This national quality programme (2012–2016) involves about sixteen to twenty care organisations initiating quality improvement projects each year. The quality indicator set will be used to establish whether quality improvements have been realised. This will ultimately lead to a data set of measurements of the quality indicators for thousands of patients and bereaved relatives. Such a large data set provides important opportunities for further psychometric testing, e.g. regarding the discriminative power of the quality indicators. Besides, this large data set can be used to see which significant patients' and relatives' characteristics should be taken into account in 'case mix adjustment procedures'.<sup>49</sup> Case mix adjustment – in the sense of statistical adjustment for differences in user characteristics between care organisations or between measurement periods – is needed for valid comparative information.

A large data set is also needed to gain more insight into 'best practice norms'. These are relative norms derived from the scores of the best scoring

care providers (e.g., the upper quartile).<sup>50</sup> The main reason for choosing relative best practice norms, rather than absolute norms is that relative norms are realistic and, therefore, may motivate healthcare professionals to improve the quality of the care they provide.

Besides the above-mentioned research plans, which have already been initiated or for which preparations have been made, some further research recommendations can be made. One recommendation concerns research on quality indicators for the palliative care of children. This is a specialised field, e.g. because of the important role of parents and the vulnerability and limited verbal communication abilities of very young children in particular. More research must be carried out to provide insight into which indicators should be adapted, omitted or added to the set for use in palliative care for children. It is recommended to start with the consultation of experts (including the parents and caregivers of sick children), who should critically examine the current set of quality indicators. These experts must be given the opportunity to come up with topics or quality indicators that are missing, and must also be encouraged to indicate indicators that are not relevant in paediatric palliative care.

It is also recommended that the quality indicator set and the related CQ-index PC are further tested in mental health institutions. Most mental health institutions have few patients receiving palliative care, which is one reason why we did not collect much data in the testing phase in these settings. However, palliative care has to be of high quality and to be carefully monitored in these settings as well.

Another recommendation for future research concerns the comparison of data collection methods. It would be interesting to investigate whether there are differences in scores between patients who complete the CQ-index PC by means of an interview and patients who fill in a written questionnaire. Socially desirable answers may be given more frequently when patients complete the CQ-index during a face-to-face interview than when they complete a (more anonymous) written version.

Finally, recommendations can also be made from an international perspective. It is important for the purpose of international quality comparisons to use the same quality indicators in different countries. A

minimum international set of quality indicators could be developed on the basis of existing quality indicators. Using such a minimum set of indicators will enable quality to be measured in a structured and comparable way, and subsequently enable a comparison of the quality of palliative care in different countries and different healthcare systems. Initially, the minimum set could focus on quality indicators for physical symptoms (e.g. the percentage of patients with moderate to severe pain) or other quality indicators within the physical care domain, since those have been developed furthest and are in widest use in various countries.<sup>8</sup> However, if justice is to be done to the broad, comprehensive character of palliative care, it is important that ultimately indicators for the psychosocial and spiritual care domains are also included in the international minimum set, as well as indicators addressing support for relatives.

Another recommendation concerns translating, testing and validating the CQ-Index PC in languages other than Dutch. Researchers in other countries who wish to measure the quality of palliative care from a user perspective could find the CQ-index PC a useful instrument. This would enable cross-country comparisons of the quality of palliative care from the perspective of palliative care patients and bereaved relatives.

### ***Recommendations for research regarding the palliative care continuum***

A convenient sample of GPs was used for the qualitative interview study. Future quantitative research is recommended in which the findings from the interview study – such as differences in recognising palliative care needs in various patient groups – are verified among a larger group of GPs. This would provide a more complete and generalisable picture of the recognition of the need for palliative care by GPs.

Treatment aims (cure, life prolongation or palliation) in the last three months before death were explored in the study based on retrospective registrations by GPs. It would also be interesting to investigate treatment aims in earlier stages of the palliative care continuum and, for instance, explore the extent in which treatments aimed at palliation are important shortly after a life-threatening diagnosis. This interest is in line with the increasing awareness of the importance of a timely start to palliative care.

Future research is also recommended to provide a better understanding of how treatment aims shift during a certain time period. According to Lynn and Adamson's model, an emphasis on curative treatment gradually shifts to an emphasis on palliative treatment as death is near. It would be fascinating to conduct a prospective longitudinal study among different patient groups, including patients with various types of cancer, to investigate the shifts in treatment. The timing of shifts in treatment aims may differ between different types of cancer, related to differences in survival times for patients with various cancer types (e.g. lung cancer has a shorter average survival time than breast cancer).

All studies in the second part of this thesis are based on the GP's perspective. It is important to investigate elements of the palliative care continuum from other perspectives too, e.g. from the perspective of patients, relatives, medical specialists, nurses or other relevant healthcare providers. The 'triangulation' of various perspectives enables a more complete picture to be obtained of the continuum of care, starting at the point of a life-threatening diagnosis or condition and ultimately ending in the patient's death and aftercare for relatives.

### ***Final remarks***

This thesis has addressed two current issues in palliative care: the development of quality indicators and the increasing awareness that palliative care is part of a care continuum starting early in the trajectory of a life-threatening condition. The developments described in this thesis also illustrate that Dutch palliative care has come of age in the past couple of decades. Nevertheless, palliative care continues to evolve, in the Netherlands as well as abroad. Quality indicators are being developed further and used more frequently in other countries as well (e.g. Belgium, Germany, USA and Australia). International comparisons using quality indicators for palliative care may be the next step to take.

It can also be expected that the national and international interest in the early initiation of palliative care, and related concepts like advance care planning, will be taken further in future, resulting in care innovations and new research projects. The growing groups of patients with incurable chronic diseases and frail older persons deserve continuing attention in palliative care research, practice and policy today and in the decades to come.

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