

New Developments in Palliative Care:
quality indicators and the
palliative care continuum

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VRIJE UNIVERSITEIT

**New Developments in Palliative Care:
quality indicators and the
palliative care continuum**

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de Vrije Universiteit Amsterdam,
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General Introduction

Palliative care has come of age in the past couple of decades in Western Europe. Specialised palliative care in the Netherlands was launched in the 1980s with the introduction of hospices, i.e. small-scale care facilities for terminally ill patients. Dutch hospice pioneers were inspired by the work and publications of Dame Cicely Saunders of the St. Christopher's hospice in London¹ and the Swiss-American psychiatrist Elisabeth Kübler-Ross.² In hospices, terminally ill patients are cared for in a home-like environment, with much attention for their physical, psychosocial and spiritual care needs. Influenced by the hospice movement, healthcare providers in other Dutch care settings also became increasingly interested in palliative care. All in all, the number of general and specialised facilities for palliative care in the Netherlands has increased significantly in the last fifteen years.^{3,4}

Since the mid 1990s, the development of palliative care has been supported by the government. In 1998, the former Minister of Health, Welfare and Sports, Professor Borst, provided a budget for research, innovation and consultation in the field of palliative care. The Minister's view was that support was needed in particular for the expertise and work of 'generalist' palliative care providers, for instance general practitioners (GPs) and home care nurses. Representatives of the Dutch government consider palliative care mainly as 'generalist' care on the assumption that palliative care has to be accessible for everyone who is in need of it. Hence palliative care has to be integrated into the regular healthcare system, in which the GPs – as gatekeepers for specialised facilities and as family doctors – have a pivotal role.

Subsequent Ministers and State Secretaries continued the policy of Minister Borst. They all reserved financial budgets for the promotion of palliative care. In 2008, the influential Plan for Palliative Care 2008–2010 was released by the then State Secretary.⁵ This plan focused on the further development of palliative care in the Netherlands, irrespective of the patient's location. The Plan aimed to promote the best possible quality of life and – ultimately – a good quality of dying for patients with a life-threatening illness. Two policy priorities specified in the Plan were (a) more transparency in the quality of palliative care through the use of quality indicators and (b) promotion of a timely start of palliative care within the so-called 'palliative care continuum'.^{5,6} In subsequent years these policy priorities were highlighted

and refined⁷, and they also form the background to the research presented in this thesis.

Quality indicators for palliative care

Good quality care can be defined as care of a high standard which is efficient, effective and patient-oriented and also matches patients' real needs.⁸ Increasing attention for the quality of palliative care can be seen nationally as well as internationally. For instance, in 2009 the European Association for Palliative Care (EAPC) pleaded for common quality standards in the 'White Paper on standards and norms for hospice and palliative care in Europe'.⁹ In addition, the National Consensus Project (NCP) for Quality Palliative Care in the United States developed guidelines for the quality of palliative care and defined preferred practices to promote quality improvement in palliative care.¹⁰

Furthermore, the Council of Europe has formulated common viewpoints about palliative care, which also include statements about quality indicators.¹¹ 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 pleaded for the identification of practical indicators that can be used to check what progress has been made in patient care over a given period. Quality indicators can be defined as "measurable aspects which give an indication of the quality of care, and which concern the structures, processes or outcomes of care."¹² Measuring quality indicators makes the quality of care transparent for patients and other stakeholders, and can provide guidance for quality improvements.

As said, the Dutch Ministry of Health, Welfare and Sports also promotes transparency in the quality of care. Hence, the use of quality indicators is fostered, not just in palliative care but also in other care domains, such as long-term residential care and curative hospital care. This government policy has resulted in recent years in a number of sets of quality indicators for various healthcare domains, often produced by researchers in cooperation with the Ministry of Health, the Health Care Inspectorate, representatives of patient organisations, umbrella organisations representing healthcare providers, and healthcare insurers.^{13,14}

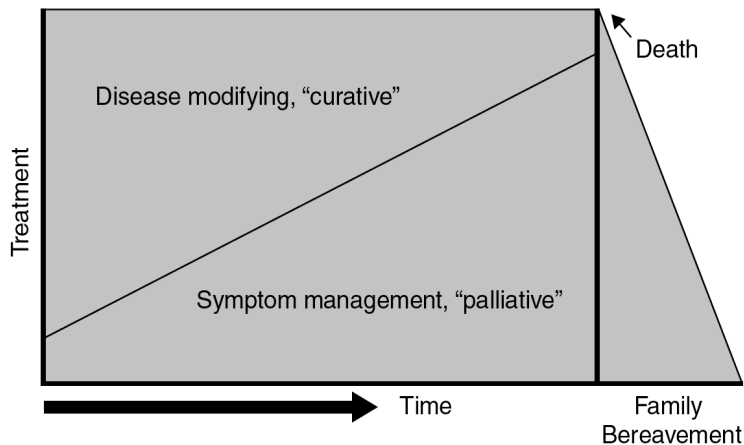
Quality indicators can be relatively 'objective' in nature, such as quality indicators for the prevalence of symptoms in patients receiving palliative care. In addition, subjective quality indicators can be used reflecting care providers' or care users' appraisal of the quality of care. In the Netherlands, there is a strong emphasis on measuring quality indicators from the perspective of care users. Structured questionnaires called Consumer Quality Indices (CQ-indices) are often used to measure such quality indicators. CQ-index instruments combine questions on actual care experiences with questions about how important care users find specific aspects of care.

In 2008–2010, a coherent set of quality indicators for palliative care were developed as well as a related CQ-index Palliative Care. The development of these indicators formed an elaboration of a key part of the above-mentioned government Plan for Palliative Care.⁵ The funding was received from the Netherlands Organization for Health Research and Development (ZonMw). The first part of this thesis describes how this set of quality indicators and the related CQ-index for palliative care were developed.

Palliative care as a care continuum

As said, another current policy priority is the promotion of a timely start to palliative care, early in the disease trajectory. Until about 10 years ago palliative care focused mainly on the care for terminal patients. Today, care providers, policymakers and researchers are increasingly aware that palliative care may already start months, or even years before death. In the influential RAND Paper 'Living Well at the End of Life. Adapting Health Care to Serious Chronic Illness in Old Age', Joanne Lynn and David Adamson presented palliative care as a continuum⁶, see Figure 1.1 below. Palliative care starts early in the disease trajectory. The initial emphasis on curative or life-prolonging treatments decreases gradually, shifting to an emphasis on palliation. Curative treatments and life-prolonging treatments are treatments aimed at modifying the disease, as opposed to palliative treatments, which focus on the management of pain or other symptoms.

Figure 1.1 The palliative care continuum (Lynn and Adamson, 2003)



Lynn and Adamson published their RAND Paper in 2003, and in later years their schematic representation of the palliative care continuum was adapted by many authors (e.g. 15-17). However, the essence remained the same, namely, the initiation of palliative care early in the disease trajectory, with simultaneous curative and palliative treatment in the first instance and an increasing emphasis on palliation as death approaches.

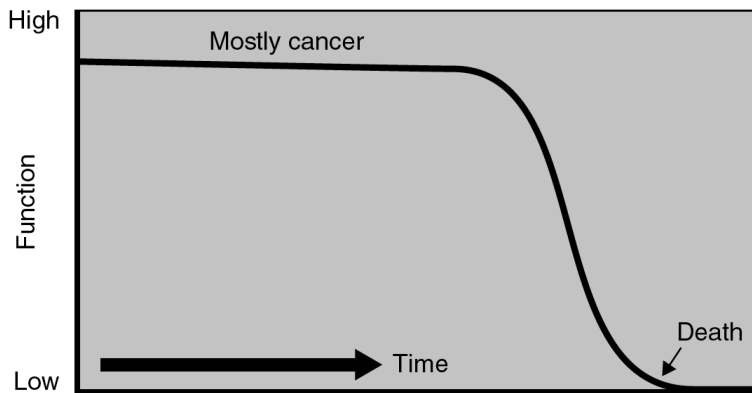
So far, there is little empirical data available on the timing of the transition from curative or life-prolonging treatments to palliative treatments and the possible coexistence of various treatment aims. One of the issues addressed in the second part of the thesis is what are the important treatment aims in the last three months of life for cancer patients versus patients with another life-threatening disease, and how these treatment aims may change as death approaches. An additional topic addressed in this part of the thesis is whether different treatments actually coexist in practice.

Although individual disease trajectories may differ within patient groups¹⁸, in contemporary literature on palliative care often general, common trajectories for specific groups of patients are presented. For example, Lynn and Adamson described three common disease trajectories, presented in Figure 1.2, that may also affect the way the palliative care continuum takes place. The first common trajectory, a trajectory often seen in patients with cancer, is characterised by a relative short period of evident decline after a

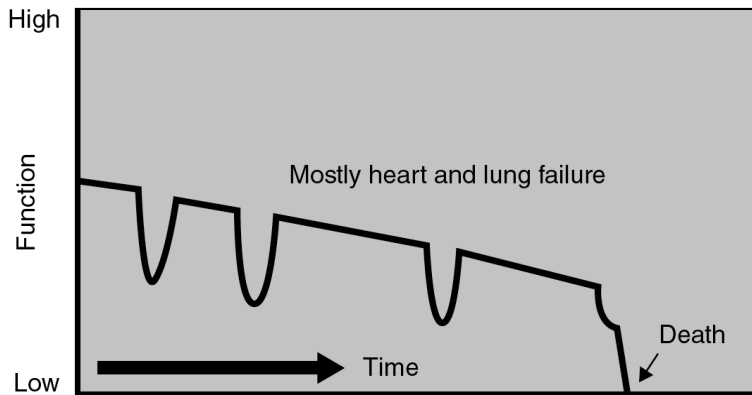
substantial period of comfort and high functioning. In contrast, the common disease trajectory of patients with heart failure or COPD is characterised by long-term limitations, intermittent exacerbations and remissions, resulting in a relatively sudden death. Finally, in the frail elderly, such as people with dementia, there is often a prolonged gradual decline towards death

Following on from these three common trajectories, it was expected that GPs would identify a need for palliative care in a different way for different patient groups. This issue is also explored in the second part of the thesis. At the end of the palliative care continuum is the patient's death (see Figure 1.1). Timely recognition that death is imminent as well as a timely diagnosis may be important in achieving a good quality of dying and giving a patient the opportunity to take leave properly. The second part of the thesis therefore also addresses the timing of when the diagnosis of the disease that ultimately led to death is made and of the GP's recognition that death is imminent. Also the information sources used regarding the diagnosis or the identification of imminent death are examined, and differences in this regard between patients with cancer and patients with another cause of death are presented.

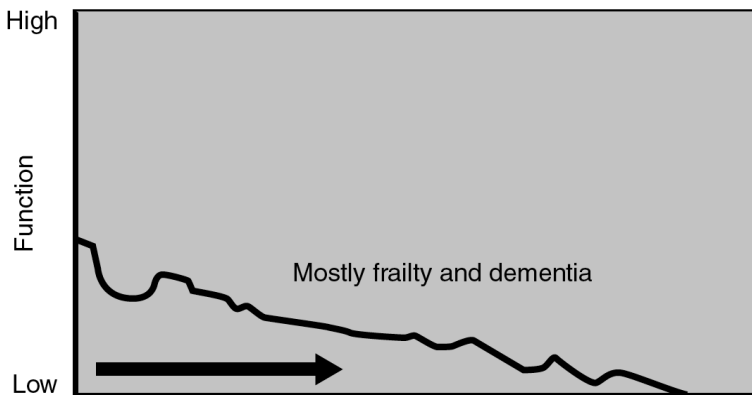
Figure 1.2 Disease trajectories at the end of life.



Short period of evident decline



Long-term limitations with intermittent serious episodes



Prolonged dwindling

Main research questions and structure of this thesis

Part 1 (Chapters 2, 3 and 4)

Measuring the quality of palliative care is the central topic in the first part of this thesis. The related research questions can be summarised in two main questions:

1. What quality indicators are suitable for measuring the quality of palliative care in various settings?
2. 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 development and initial testing of a set of quality indicators for palliative care is described in Chapter 2 (addressing research question 1).

The development of the CQ-index Palliative Care is described in Chapters 3 and 4, giving the patients' version and the version for bereaved relatives respectively (see research question 2).

Part 2 (Chapters 5, 6 and 7)

Research related to the palliative care continuum is discussed in the second part of this thesis. The research questions addressed are:

3. When and how do GPs recognise a need for palliative care?
4. What are the important treatment aims in the last three months of life for patients with a non-sudden death?
5. How long before death is the diagnosis of the disease that ultimately led to death made?
6. On the basis of what kind of information sources do GPs become aware of the diagnosis of the disease that ultimately led to death?
7. How long before their patients' death do GPs recognise that death is imminent?
8. On the basis of what kind of information sources do GPs recognise that death is imminent?
9. Are there any differences between GPs' patients dying from cancer and GPs' patients dying from non-cancer diseases with regard to these issues addressed in the foregoing research questions?

In Chapter 5, GPs' identification of patients' need for palliative care is addressed (see research questions 3 and 9).

Chapter 6 presents the treatment aims for patients with cancer and patients with other chronic diseases (see research questions 4 and 9).

Chapter 7 focuses on GPs' identification of the diagnosis and of the imminence of death in patients with cancer and patients with other non-sudden death causes (see research question 5, 6, 7, 8 and 9).

Finally, Chapter 8 presents a general discussion of the major findings, and recommendations are made based for research, policy and practice.

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Part I

Quality Indicators



***A new set of quality indicators for palliative care:
process and results of the development trajectory***

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ABSTRACT

Context

In some countries (the United States in particular), quality indicators for palliative care have already been developed. However, these quality indicators often cover one specific setting or target group, for example, palliative cancer care or palliative home care.

Objectives

This article describes the development and initial testing of a set of quality indicators for palliative care, applicable for all settings in which palliative care is being provided for adult patients in The Netherlands.

Methods and Results

In the first phase of the project, an inventory was made of existing relevant quality indicators. Most quality indicators focused on the process or outcome of palliative care, and quality indicators for the structure of palliative care were rare. Most of the existing quality indicators fall within the domain of physical care, and very few concern the social and spiritual domains of palliative care. In the second phase, a new draft set of quality indicators was developed. In addition to the previous inventory of existing indicators, interviews with patients, relatives, and caregivers provided input for the development of the draft set. Drafts of the set were tested among experts. In the third phase, the feasibility and usability of a draft set was established in 14 Dutch care organizations providing palliative care.

Conclusion

As a result of these phases, a set of quality indicators for palliative care has been developed, consisting of 33 indicators for palliative patient care and 10 indicators for support for relatives before and/or after the patient's death.

INTRODUCTION

In palliative care, the quality of life of patients and their families is greatly influenced by the quality of the care that is provided. To improve palliative care wherever needed, the quality of the care has to be assessed and monitored over time. Quality indicators may play an important role in this regard. In this article, we define quality indicators as “measurable aspects which give an indication of the quality of care, and which concern the structures, processes or outcomes of care”.¹ Structure indicators refer to the organization of the care (e.g., whether a care organization has a multidisciplinary palliative care team), whereas process indicators refer to the quality of the care process (e.g., whether professionals work according to specific clinical guidelines). Outcome indicators often concern the clinical outcomes of care, for instance, the percentage of patients with (un)relieved pain or other symptoms.² The percentage of patients with positive or negative opinions about the quality of the care is another example of an outcome indicator.

Prominent policy reports and publications on palliative care indicate that there is increasing interest in the development and use of quality indicators. For instance, the Council of Europe³ 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.” Recently, the Council of Europe in 2009 reconfirmed this point of view and pleaded for the identification of practical indicators that can be used to check what progress has been made in patient care over a given period. Moreover, in the past decade, a variety of research publications have focused on quality indicators for palliative care. For example, Earle et al.^{4,5} and Grunfeld et al.⁶ described indicators for assessing the quality of end-of-life care for patients with cancer, and Twaddle et al.⁷ described quality indicators for palliative care in academic medical centers. In Italy, Peruselli et al.⁸ developed quality indicators for palliative home care.

In The Netherlands, interest in quality indicators also has increased. In several subsequent policy statements, the Dutch Ministry of Health^{9,10} has stressed the need to develop and implement quality indicators. In line with this, the Ministry commissioned the development of a set of quality indicators for palliative care that should be applicable for all different

settings of palliative care: not only at home, in hospices, and in palliative units but also in hospitals, nursing homes, homes for the elderly, mental health institutions, and institutes for the mentally retarded. It also was stipulated that the set should primarily consist of outcome indicators because the Ministry considers that the care organizations are responsible for organizing the structure and process of the care they provide, ensuring that the outcomes for patients and relatives are good. The set of indicators should not only be applicable for internal use within a health care organization but also should have the potential to be applicable for external use. Internal use means that care organizations use the indicators to assess the quality of the care they provide and subsequently to make quality improvements within their organization, where needed. External use means that the indicators (also) can be used to provide transparent quality information for external parties, such as patient organizations and the Health Care Inspectorate.

The purpose of this article is to describe the development and initial testing of this new set of quality indicators, which had to be applicable in all settings where palliative care is being provided for adult patients in The Netherlands. The following

main research questions will be addressed:

1. Which quality indicators for palliative care have previously been developed?
2. What are the characteristics of the new set of quality indicators?
3. Is this set feasible and usable in various palliative care settings?

METHODS AND RESULTS

The development of the set of quality indicators was characterized by a phased approach, which is presented in Table 2.1. The project was carried out over a two-year period, namely in 2007 and 2008.

Table 2.1 Overview of project stages

Phase	Aim and approach	Results/conclusions
<p>Phase 1 INVENTORY</p> <p>National inventory of existing quality indicators and relevant documents</p>	<p>Several Dutch literature sources were searched to obtain relevant indicators in the Dutch language</p>	<p>A final set of 25 relevant quality documents were reviewed. Conclusion: No Dutch quality indicators specifically focusing on palliative care existed.</p>
<p>International systematic literature review on existing quality indicators</p>	<p>Several international databases (PubMed, PsycINFO, EMBASE and CINAHL) were searched to track down indicators. Keywords and medical subject headings for palliative care and quality indicators were combined. First selection on basis of title and/or abstract, and second selection on basis of full text. Characteristics of indicators were extracted and a methodological analysis was performed.</p>	<p>16 publications were found which described a total of 142 quality indicators for palliative care. Most were process indicators (n= 82) and outcome indicators (n= 57). Most indicators applied to only one specific setting or to very specific target groups. The indicators identified in this international systematic review gave input to the expert meeting in the subsequent phase.</p>

- Table 2.1 continued -

Phase Phase 2 DEVELOPMENT AND TESTING DRAFT SET	Aim and approach	Results/conclusions
<p>Expert meeting and subsequently expert round by e-mail</p>	<p>Main aims of the meeting with 36 experts: to inform them about the project and to choose highly relevant themes and indicators. An overview of themes and existing indicators was sent before the meeting. The experts were asked:</p> <ul style="list-style-type: none"> * to prioritize themes for indicators * to indicate which themes or indicators were missing <p>After the meeting, an overview of the themes and indicators which were given high priority was sent by e-mail to the experts. They were asked to comment again on the prioritized themes and indicators.</p>	<p>The themes "pain" and "fatigue/insomnia" were considered highly relevant, as well as the themes "anxiety", "depression/somnolence" and "adequacy of information and communication"</p> <p>Experts missed indicators for aftercare</p> <p>Experts also indicated that some existing international quality indicators were relevant but have to be adapted to fit with our project in order to result in indicators that can be used in all settings of palliative care. This expert advice prompted our decision to develop a new set of quality indicators.</p>

- Table 2.1 continued -

Phase	Aim and approach	Results/conclusions
<p>Phase 2 DEVELOPMENT AND TESTING DRAFT SET</p> <p>Focus group interviews and/or individual interviews with patients, relatives and caregivers</p>	<p>To determine essential components of quality of care:</p> <ul style="list-style-type: none"> * two focus group interviews were held with a total of 18 healthcare providers, and one focus group with three bereaved relatives. * individual interviews were held with three patients and one relative. In the analysis, these interviews were combined with findings of previous interviews with 19 patients and with 23 relatives. 	<p>Important quality aspects that were frequently mentioned were: respect for autonomy, personal/warm attention from care providers, and expertise and continuity of caregivers. These quality aspects were somewhat underexposed in the themes and indicators prioritized in previous phases, so these additional themes were integrated in the draft set of indicators.</p>
<p>Testing drafts in the steering committee</p>	<p>On several occasions during the project, the steering committee, consisting of various stakeholders, met. A main task of this committee was to reflect the draft set of indicators.</p>	<p>A main comment of the steering committee was that most quality indicators should concern the perspective of the patients or the relatives, rather than the perspective of caregivers. They also recommended a rather short set, since patients, relatives and care providers must not be burdened by the assessments.</p>

- Table 2.1 continued -

Phase PHASE 3 TESTING IN DAILY PRACTICE	Aim and approach	Results/conclusions
Measurement of indicators	<p>During a two-month period the draft set was tested for feasibility and usability in different palliative care settings. Characteristics of the 14 participant institutions and the patients and relatives involved in this testing phase are presented in table 2.2.</p> <p>A total of 43 quality indicators were measured distinguished in:</p> <ul style="list-style-type: none"> * indicators concerning actual care experiences of patients, measured with the CQ-index Palliative Care * indicators related to the prevalence of symptoms, measured with Numeric Rating Scales * indicators concerning actual care experiences of relatives, measured with the relative version of the CQ-index Palliative Care 	For results/conclusions, see below

- Table 2.1 continued -

Phase PHASE 3 TESTING IN DAILY PRACTICE	Aim and approach	Results/conclusions
<p>Evaluation of usability and feasibility of the measurements</p>	<p>After the two-month-measurement period, contact persons (often nursing managers) completed a short evaluation questionnaire and participated in an open interview. The aim was to gain insight into the care providers perspective on the feasibility (e.g. time investment) and usability (e.g. whether the indicators can be used for quality improvement).</p> <p>The usability and feasibility of the quality indicator set was also discussed in a final group meeting with seven contact persons from the participating institutions and two other people</p>	<p>The contact persons reported that the time investment was feasible, for themselves and also for the patients. The quality indicator assessments had provided more insight into the quality of the care and also some necessary quality improvements.</p> <p>The positive results of this testing phase, allowed us to proceed to the final phase in this development trajectory (see phase 4)</p>

- Table 2.1 continued -

Phase Phase 4 FINAL ADJUSTMENTS OF THE QUALITY INDICATOR SET	Aim and approach	Results/conclusions
	<p>Some final adjustments were made. A main reason for adjusting a quality indicator was for example, that members of the steering committee indicated that the description of some quality indicators was not specific enough for palliative care.</p>	<p>The final set now consists of 43 (mainly outcome) indicators, of which 33 concern palliative care provided to patients, and 10 concern support for relatives.</p>

Phase 1: Inventory

National Inventory

In the first half of 2007, several sources were searched to obtain relevant indicators in the Dutch language, for instance, websites focusing on palliative care (e.g., www.ikcnet.nl; www.palliatief.nl), the library catalog of The Netherlands Institute for Health Services Research (NIVEL), and documents suggested by experts. This resulted in 94 potentially relevant documents, which were analyzed by one of the authors (H. E. B.) based on a schedule with questions including the type of document (e.g., concerning indicators, clinical guidelines, or quality instruments), the quality aspects described, the aim, the target group, and the organizational setting.

The most important conclusion that could be drawn from the national inventory was that, in The Netherlands, there are many clinical guidelines and other quality-related documents concerning palliative care. However, none of these guidelines or documents describes quality indicators for palliative care in detail. One general quality indicator set was found¹, but this set was not specific for palliative care.

International Systematic Review

In the second half of 2007, we also systematically searched several international databases, including PubMed, PsycINFO, EMBASE, and CINAHL. Keywords and medical subject headings for palliative care and quality indicators were combined. Detailed information about the search strategy has been published elsewhere.² For this international systematic review, we applied the following inclusion criteria: 1) the focus in the literature to be reviewed had to be on the description or development of specific quality indicators for palliative care; and 2) the description of the indicator involved a numerator and a denominator, or the numerator and denominator could be directly deduced from the description of the indicator, or a performance standard was given.

The searches resulted in 650 potentially relevant references. Subsequently, a selection was made on the basis of the title and/or abstract of the 650 references, according to the inclusion criteria. This resulted in 33 potentially relevant references. Second, the full text of each reference was read, after which the reference was finally excluded or included on the basis of the

inclusion criteria.

This final selection resulted in 16 publications, mainly originating from the United States (among which was an Agency for Healthcare Research and Quality contribution¹²), meeting the inclusion criteria. They described a total of 142 quality indicators. In a subsequent analysis, the main characteristics of the indicators were extracted. Finally, a methodological analysis was performed, with the AIRE (Appraisal of Indicators through Research and Evaluation) instrument.¹³ The AIRE instrument is meant to assess whether the aim and the organizational context of the quality indicators are clearly described and whether the quality indicators are research based.

One conclusion of the review was that most of the indicators were process indicators (n= 82) and outcome indicators (n= 57), and far fewer structure indicators (n= 5) were found. Indicators concerning the social and spiritual aspects of palliative care were underrepresented. Another conclusion was that many of the existing indicators applied to only one specific setting or target group.^{4-8,14-20}

The scores, according to the AIRE instrument, showed that the methodological quality of the indicators varied. Some sets had clearly defined numerators, denominators, and/or performance standards, whereas the content of other sets was not described in detail. More details of the methods and results of the systematic review have been published elsewhere.²

Phase 2: Development and Testing of Draft Set

Consultation of Expert Panel

An essential stage in the development of the set of quality indicators was the consultation of 36 experts, representing medical practice, research, and palliative care policy making. This was considered to be important because the indicators were intended to reflect, as much as possible, the experiences of target groups, and we expected that this would enhance acceptance in the field of palliative care.

The expert meeting was held at the end of 2007. A classification scheme of existing indicators derived from the national inventory or from the systematic international review was sent to the experts before the meeting.^{21,22} The experts were asked to prioritize themes for indicators and also determine which existing quality indicators reflected these themes the most, in view of their applicability and relevance for the Dutch situation. Furthermore, they were asked to indicate which quality indicators were missing.

After the meeting, the researchers analyzed the reactions of the experts and subsequently developed a new draft set of indicators. This new draft set was then sent by e-mail to the experts, and they were asked to comment again on the indicators and the classification.

Focus Groups and Interviews

Subsequently, several focus group and individual interviews were held with patients, relatives, and caregivers. The aim of the interviews was to investigate essential components of quality of care from a user perspective, so that these could be taken into account in the development of the set of indicators.

Mid-2008, two focus group interviews were held with a total of 18 caregivers (mainly nurses and volunteer care providers). There was also one focus group interview with three relatives of patients who had recently died after a long period of illness. Furthermore, three patients and one relative were individually interviewed. Various inpatient and outpatient settings were represented in the interviews

All focus group discussions and interviews had an “open approach,” in the sense that we initiated the focus group discussions with open-ended questions, such as “Describe some positive and negative care experiences” and “According to you, what makes good quality care?” The patients and relatives were asked to answer from their own perspective, whereas professional and volunteer care providers were asked to identify with the needs and wishes of patients and relatives. The interviewed patients, relatives, and care providers were not asked to assess existing quality indicators (in contrast to the experts in the foregoing subphase). The main reason was that we did not want to influence the participants too much by letting them know what quality indicators already existed.

The individual interviews were recorded and typed verbatim. The focus group interviews were not all typed out but were summarized in sheets in dialogue between the participants. The transcribed interviews and sheets were then analyzed qualitatively by the first author. She read and reread the material and inductively coded the aspects of care that were mentioned as crucial for high-quality palliative care.

Subsequently, the findings from the interviews performed in 2008 were compared and combined with the findings of qualitative interviews with 19 patients and 23 relatives in a previous study carried out in 2000 by our research group. These previous interviews also focused on what care users find important for high-quality palliative care.²³

The process and outcomes of the analysis were discussed by the first author and the co-authors. Important quality aspects that emerged from the analysis, and which were frequently mentioned in the interviews, were “taking wishes and needs into consideration (autonomy),” “personal/warm attention,” and “expertise and continuity of caregivers.” These quality aspects were somewhat underexposed in the themes and the indicators identified in previous phases. At the end of this phase, we ensured that the issues mentioned in the interviews were reflected in several indicators in the draft set.

Testing Different Drafts in the Steering Committee

On several occasions during the development, the draft sets were discussed with the steering committee, which consisted of various stakeholders, for

example, representatives from patient organizations, national umbrella organizations in the field of palliative care, the Ministry of Health, and the Health Care Inspectorate. The main task of the steering committee was to reflect on the draft sets.

One of the points of interest mentioned repeatedly by the steering committee was that, if possible, the quality indicators should be assessed from the perspective of the patients or the relatives, rather than from the perspective of the caregivers. Furthermore, the steering committee often emphasized that patients, as well as relatives and health care providers, must not be burdened with too many questions. This implied that the set of indicators should not be too extensive.

Phase 3: Testing in Daily Practice

Aim of the Testing Phase

During a two-month period (end of 2008), the indicator set was tested for feasibility and usability in practice. Feasibility was measured by taking into account the time investment for the health care professionals, patients, and relatives involved. In addition, feasibility was measured by taking into account the availability of contact persons/caregivers who wanted to work with the indicators and availability of patients and relatives in whom the indicators could be measured during a rather limited measurement period (± 2 months).

Usability concerns the extent to which the results of the indicator can be applied.²⁴ Therefore, we took into account the perception of the health care professional, that is, the quality indicator assessments can be used as input for quality improvements. Usability also refers to the usability of the instruments used to measure the quality indicators (e.g., whether or not they are too extensive for this vulnerable group). These aspects concerning feasibility and usability were measured in patients, relatives, and/or contact persons from the care organizations.

Recruitment

Fourteen Dutch care organizations formed a convenience sample and participated in the assessment. These care organizations were recruited through personal contacts of the research partners (NIVEL and EMGO

Institute). They were purposively chosen because we aimed to recruit (at least one) representative care organizations for each of the following care settings: palliative home care, hospice care, palliative hospital care, palliative day-care, palliative care in a nursing home or home for the elderly, and palliative care in an institute for the mentally retarded or mental health institution.

Within the 14 participating care organizations, all patients or relatives who met the inclusion criteria were invited to participate. The inclusion criteria for patients were a maximum life expectancy of six months or less and/or receiving palliative treatment. The inclusion criterion for relatives was direct involvement in the care for patients who had died after a long illness (i.e., not suddenly) between six weeks and six months previously.

Assessment of the Quality Indicators

About half of the 43 quality indicators in the draft set concerned the experiences of patients or relatives with the care received. These indicators were measured with the CQ-index Palliative Care (CQ-index PC). This is a structured questionnaire containing questions on care experiences.²⁵ The CQ-index PC consists of a patient version and a relative version. The relatives, as well as patients living at home, received the questionnaire by post, and patients in inpatient or hospice settings responded to the questionnaire verbally during an interview conducted by the researchers or trained interviewers. The patients were asked to complete the CQ-index PC based on their experiences with the care delivered in the previous week by the care institution from which they received the questionnaire. Bereaved relatives who received the CQ-index PC relative version were asked to complete the questionnaire by taking into account the care received from the last health care institution involved.

The other half of the set concerned quality indicators about the prevalence of symptoms, that is, pain, fatigue, shortness of breath, constipation, anxiety, or feeling depressed. These quality indicators were measured with numerical rating scales (NRSs), ranging from zero to 10.²⁶ The NRSs were completed by the patients and administered by a caregiver (often a nurse). For patients with moderate or severe cognitive impairments, NRSs were not used, but observation scales that are appropriate for this target group.²⁷

In principle, the patients who were involved in the assessment of the

indicators regarding care experiences were the same as those who were involved in the assessment of indicators regarding the prevalence of symptoms. Table 2.2 presents the number of patients and relatives who participated in the testing phase.

Table 2.2 Number of patients and relatives who participated in the testing phase

Setting	Patients involved in the assessment of quality indicators for care experiences	Relatives involved in the assessment of quality indicators for care experiences	Patients involved in the assessment of quality indicators for symptoms
Two high care hospices and one volunteer-driven hospice	8	28	8
One palliative care unit in a hospital	3	3	3
One palliative care unit in a nursing home and one in a home for the elderly	6	24	3
One home for the elderly and one nursing home (no palliative care unit)	3	11	3
Two cancer units in a hospital	8	0 (in these cancer units addresses of bereaved relatives were unknown)	3
One home care organization	11	14	14
Two mental health institutions	1	1	1
One institute for the mentally retarded	0	4	10
Total	40	85	45

We did not get the impression that the patients or the relatives felt emotionally or physically burdened by the assessments, although some

found the length of the CQ-index PC –the instrument used to measure the quality indicators for care experiences– too long. This critical comment made by about half of the respondents was the main reason why we subsequently shortened the CQ-index.²⁵

This testing phase also indicated some organizational factors that contribute to the successful application of quality indicators. One success factor is the provision of good information for caregivers about the aim of the assessments, instructions, and how to measure the quality indicators. Moreover, the availability of one contact person (e.g., a nursing manager or team coordinator) within the organization is crucial. For the recruitment of relatives after the death of a patient, it is also important that there is an updated list of the addresses of all relatives.

Evaluation Among Contact Persons

The contact persons in the participating care organizations all received a short report on the results of the quality indicator assessments, after which they completed an evaluation questionnaire. Subsequently, verbal open interviews were held with these contact persons. Both the evaluation questionnaire and the interview focused on aspects of feasibility and usability. The contact persons reported that their time investment had been feasible, and some mentioned that they had deduced improvements from the report, for example, regarding aftercare for relatives. It appeared that relatives were not always informed about the possibilities of aftercare.

Finally, all contact persons in the participating care organizations were invited to attend an evaluation meeting. The discussions in this meeting also showed that, in general, the contact persons were positive about the usability of quality indicators because the assessments had provided more insight into the quality of the care. However, some of them pointed to the fact that the indicators concern multidisciplinary care. As a consequence, it was sometimes unclear which health care provider was responsible for low scores for certain quality indicators. It was concluded that quality indicators only give an indication of good or bad quality care, and that when scores are low, additional inquiries must be made to find out where things go wrong in the multidisciplinary chain of palliative care.

Phase 4: Final Adjustments of the Quality Indicator Set

After the testing phase, the findings were discussed with the steering committee. These discussions led to some adjustments of the quality indicator set. For example, we reformulated the draft indicator “The extent to which patients received information regarding life expectancy” because it turned out that some patients had difficulties with the underlying question about life expectancy. Therefore, we changed the indicator to “The extent to which patients receive information about the expected course of the illness.” Furthermore, some indicators were omitted (i.e., the indicator “The extent to which patients experience the meals as good”) because these were not very specific for palliative care.

The final set now consists of 43 (mainly outcome) indicators, most of which (33 indicators) concern the palliative care provided for the patients, and the rest (10 indicators) concern support and aftercare for the relatives. The final set of quality indicators is described in more detail below.

Description of the Quality Indicator Set

The set of quality indicators for palliative care is subdivided into the following main categories:

Quality Indicators Concerning Palliative Care for Patients

- 1 Management of pain and other physical symptoms
- 2 Care for psychosocial well-being
- 3 Care for spiritual well-being
- 4 General aspects

Quality Indicators Concerning Support or Aftercare for Relatives

- 5 Care for psychosocial and spiritual well-being of relatives
- 6 General aspects
- 7 Aftercare

Quality indicators concerning the prevalence of symptoms are expressed as “The percentage of patients... and so on... ,” with numerators and denominators. Quality indicators concerning actual care experiences, measured with the CQ-index PC, are mostly expressed as “The extent to which patients... and so on... ” In these quality indicators, no numerators or denominators are presented because they are assessed by calculating scale

means (and not percentages). Tables 2.3 and 2.4 present two examples of quality indicators (translated from Dutch). All the quality indicators that have been developed are outcome indicators, except one: the indicator “Presence of documentation concerning the desired care and treatment at the end of life” (Table 2.5).

Table 2.3 Example of a quality indicator concerning the prevalence of a symptom

Percentage of patients with moderate to severe pain	
Reason for indicator	Pain is a common symptom in the palliative phase. The quality of both pharmacological and nonpharmacological interventions influences the severity of pain.
Numerator	The number of patients with a pain score of 4 or above on the NRS (average over three days).
Denominator	The total number of patients for whom this indicator is measured.
Do not measure	Comatose and deeply sedated patients.
Registration source: patients, according to their scores on the NRS described here	This indicator must be measured <u>on three consecutive days (1x a day)</u> on a NRS. As far as possible, the measurements should take place at the same time each day (e.g. before the daily care rounds). The question is: Which score from zero to 10 would you give for pain? <i>The patient must decide on the score independently. If the patient's health status permits, the patient should preferably also hold the pen. A score list with NRS scales could also be left with the patient. This is, in particular, important for patients (e.g. living at home) who do not have daily contact with a care provider.</i>
Registration of patients with cognitive impairments (e.g. patients with dementia or in institutes for the mentally retarded):	Pain can be measured in patients with moderate to (very) severe cognitive impairments, but not with an NRS. Pain in these patients, can be measured with a pain observation instrument that was specifically developed for the measurement of patients with cognitive impairments, namely the Rotterdam Elderly Pain Observation Scale, see Van Herk 2008. ²⁷ Measurements with this instrument should also take place <u>on three consecutive days (1x a day)</u> , as far as possible at the same time each day (e.g. before the daily care rounds).

Table 2.4 Example of a quality indicator concerning actual care experiences

Extent to which patients receive support for their physical symptoms	
Reason for indicator	Pain, fatigue, shortness of breath and constipation are symptoms that frequently occur in the palliative phase. The quality of both pharmacological and nonpharmacological interventions influences the severity of a patient's physical symptoms.
Do not measure	Patients with moderate to (very) severe cognitive impairments, young children, and comatose and deeply sedated patients
Registration source: items of the patient version of the CQ-index PC	<p>Do you receive support when you are in pain?</p> <p><input type="checkbox"/> never</p> <p><input type="checkbox"/> sometimes</p> <p><input type="checkbox"/> usually</p> <p><input type="checkbox"/> always</p> <p><input type="checkbox"/> not applicable (because I have no pain)</p> <p>Do you receive support when you are tired?</p> <p><input type="checkbox"/> never</p> <p><input type="checkbox"/> sometimes</p> <p><input type="checkbox"/> usually</p> <p><input type="checkbox"/> always</p> <p><input type="checkbox"/> not applicable (because I am not tired)</p> <p>Do you receive support when you have shortness of breath?</p> <p><input type="checkbox"/> never</p> <p><input type="checkbox"/> sometimes</p> <p><input type="checkbox"/> usually</p> <p><input type="checkbox"/> always</p> <p><input type="checkbox"/> not applicable (because I do not have shortness of breath)</p> <p>Do you get/receive support when you are constipated?</p> <p><input type="checkbox"/> never</p> <p><input type="checkbox"/> sometimes</p> <p><input type="checkbox"/> usually</p> <p><input type="checkbox"/> always</p> <p><input type="checkbox"/> not applicable (because I am not constipated)</p> <p><i>“Support” should be interpreted in the widest sense of the word: it can sometimes mean the attention a patient receives from care providers, but it can also mean treatment with medication.</i></p>

The examples above provide insight into various elements of the quality indicators. It is beyond the scope of this article to describe all 43 quality indicators in detail (including numerators, denominators, source of registration, and registration questions), but the entire set of quality indicators (translated from Dutch into English) is available on request. Tables 2.5 and 2.6 present an overview of the titles of the quality indicators for palliative care for patients and relatives in categories.

Table 2.5 Overview of titles of quality indicators for palliative care for patients, in categories (translated from Dutch)

Category	Name indicator
A. Management of pain and other physical symptoms	A1. Percentage of patients with moderate to severe pain A2. Percentage of patients with fatigue A3. Percentage of patients with shortness of breath A4. Percentage of patients with constipation A5. Extent to which patients receive support for their physical symptoms (pain, fatigue, shortness of breath and constipation) A6. Extent to which patients receive help with physical care
B. Care for psychosocial well-being	B1. Percentage of patients with anxiety B2. Percentage of patients who feel depressed B3. Extent to which patients receive support when they feel anxious or feel depressed B4. Extent to which patients receive attention from their caregivers B5. Extent to which patients are satisfied with the counselling aspects of "politeness" and "being taken seriously" B6. Extent to which patients experience respect for their autonomy B7. Extent to which patients experience respect for their privacy B8. Extent to which direct relatives considered that the patient had the opportunity to be alone

-Table 2.5 continued-

-Table 2.5 continued-

Category	Name indicator
C. Care for spiritual well-being	<p>C1. Extent to which patients indicate that caregivers respect their life stance</p> <p>C2. Extent to which patients indicate that they have access to a counsellor for spiritual problems</p> <p>C3. Extent to which relatives indicate that the patient had access to a counsellor for spiritual problems</p> <p>C4. Extent to which relatives indicate that the patient received support with preparations for saying goodbye</p> <p>C5. Extent to which patients indicate that they feel that life is worth while</p> <p>C6. Percentage of relatives who indicate that the patient died peacefully</p> <p>C7. Percentage of relatives who indicate that the patient had accepted her/his approaching death</p> <p>C8. Extent to which relatives indicate that there was attention and respect for the psychosocial and spiritual well-being of the patient</p>
D. Generic aspects	<p>D1. Extent to which patients in the last month before their death were in the location of their preference</p> <p>D2. Percentage of patients who died in the location of their preference</p> <p>D3. Extent to which patients know who the contact person is for the care</p> <p>D4. Extent to which patients receive information about the expected course of the illness</p> <p>D5. Extent to which patients receive information about the advantages and disadvantages of various types of treatments</p> <p>D6. Extent to which patients indicate that they receive understandable explanations</p> <p>D7. Extent to which patients indicate that they receive contradictory information</p> <p>D8. Presence of documentation concerning the desired care and treatment at the end of life</p> <p>D9. Extent to which relatives indicate that the patient was asked about her/his opinions with regard to end-of-life decisions</p> <p>D10. Extent to which patients experience the expertise and continuity</p> <p>D11. Percentage of patients who receive medical aids soon enough</p>

Table 2.6 Overview of titles of quality indicators concerning support or aftercare for relatives, in categories (translated from Dutch)

Category	Title indicator
E. Care for psychosocial and spiritual well-being of relatives	<p>E1. Extent to which, according to the direct relatives, attention was paid to their own psychosocial and spiritual well-being</p> <p>E2. Extent to which the direct relatives felt that they were treated well in all respects by the caregivers</p> <p>E3. Extent to which, according to the direct relatives, their autonomy was respected</p> <p>E4. Extent to which the direct relatives had the opportunity to be alone with their relative</p>
F. Generic (in the care for relatives)	<p>F1. Extent to which direct relatives received information that was understandable and unambiguous at the time of the patient's death</p> <p>F2. Extent to which direct relatives received information about the advantages and disadvantages of various types of treatment</p> <p>F3. Extent to which direct relatives perceived the expertise of caregivers and the continuity of care</p>
G. Aftercare	<p>G1. Extent to which direct relatives felt supported by the caregivers immediately after the patient's death</p> <p>G2. Extent to which direct relatives were informed about the possibilities of aftercare</p> <p>G3. Extent to which a final conversation or discussion was held to evaluate the care and the treatment</p>

DISCUSSION

Currently, there is increasing interest in quality indicators for palliative care. In the international systematic review that we conducted at the end of 2007, 16 publications were selected, describing a total of 142 quality indicators.² Since then, there have been several new publications concerning quality indicators for palliative care.^{24,28-36} Most of these sets of quality indicators focus on the structure or process of care, whereas our set primarily focuses on outcomes. Measuring structure or process indicators may be easier and cheaper than measuring outcome indicators because the relevant information can often be obtained from medical charts or administrative databases, whereas outcome indicators often have to be derived from the individual care

users. However, in our opinion, the perspectives of care users on the outcomes of care provide the best indications whether good quality care has been achieved.

Another difference between our set of indicators and most other sets concerns the fact that the latter are often targeted to specific populations in palliative care, such as patients with incurable cancer.^{12,24,29,31–35} In the case of cancer patients, many quality indicators focus on specific types of treatment (e.g., chemotherapy) and the side effects thereof, which make them less suitable for use in other patient groups. Characteristic for our set is that the indicators are applicable in all settings and for all adult patient groups receiving palliative care.

Also characteristic for our set is that the indicators not only address physical, psychosocial, and spiritual domains but also aftercare. Most other quality indicator sets mainly focus on physical aspects, and the social and spiritual aspects of palliative care are often underrepresented.²

To the best of our knowledge, such a broad generic set of quality indicators, which can be used in various settings, is unique. However, in this project, the set has not yet been tested in palliative care facilities for children because we considered palliative care in children as a very specific field. More research must be carried out to provide insight into which indicators in the set should be adapted, omitted, or added for use in palliative care settings for children.

Another limitation is that the set was tested in a rather small sample of 14 care organizations. Therefore, in a planned future research project, the set of indicators also will be tested for usability and feasibility in a larger sample. In a future study, we also will establish whether the set is not only suitable for internal use by care providers but also for external parties who want to have public comparative information. Comparing the quality indicator scores of different care providers can be relevant for the Health Care Inspectorate, patient organizations, or health care insurers wanting to know where the best (or worst) palliative care is provided. But before using the set for public comparisons, we first have to assess significant “case mix adjusters” and the discriminative power of the indicators. Only if future research in a larger sample establishes that the indicators do have discriminative power will we recommend their use for public comparative information (benchmarking). In

the planned future research project, we also will assess “best practice norms” for specific palliative care settings. These are relative norms derived from the scores of the best scoring care providers (e.g., the upper quartile).¹¹ The main reason for choosing relative best practice norms, instead of absolute norms, is that relative norms are realistic and, therefore, motivate health care professionals to improve the quality of the care they provide.

Conclusion

At the end of this development phase, a set of 33 quality indicators for patients and 10 for relatives is now available. This set covers all aspects of palliative care: physical, psychosocial, and spiritual care, including the support for relatives. At the moment, the set is suitable for internal use by health care organizations in various palliative care settings. Future research will establish whether the set is also appropriate for external use.

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Measuring patients' experiences with palliative care: the Consumer Quality Index Palliative Care

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ABSTRACT

Background

The Consumer Quality Index Palliative Care (CQ-index PC) is a structured questionnaire for measuring the quality of palliative care from the perspective of care users. CQ-indices assess which care aspects need quality improvement by relating answers about actual care experiences to answers about the importance of certain aspects of care.

Methods

To improve the chance that the new instrument had good content validity, a literature study and individual and group discussions were performed, and a steering committee was consulted to establish the instrument's face and content validity. The questionnaire was administered to patients with a life expectancy of six months or less and/or who were receiving palliative treatment. Descriptive analyses were carried out on the items about actual care experiences and the importance of care aspects, and on 'need for improvement' scores.

Results

Fifteen care organisations participated. 133 patients met the inclusion criteria (net response n = 85). Patients considered the following aspects most important: 'offering help in good time in acute situations', 'caregivers having the necessary expertise' and 'caregivers taking the patient seriously'. The three care aspects with the highest 'need for improvement' scores were: 'support when the patient feels depressed', 'support when the patient is anxious' and 'support when the patient has shortness of breath'.

Conclusions

The CQ-index PC provides opportunities for care organisations to assess which care aspects have the highest priority for quality improvement within their organisation. Further research is needed to assess whether the instrument has enough discriminative power to assess differences between organisations.

BACKGROUND

Providing patient-centred care is the main aim of palliative care, and so profound insight into the quality of care experienced by patients is of paramount importance. A Consumer Quality Index (CQ-index) is a structured questionnaire for measuring the quality of care from the perspective of care users.

CQ-indices assess care users' actual care experiences but do not ask directly about their satisfaction with care. A definition of satisfaction is 'fulfilling expectations, needs or desires'.¹⁻² Satisfaction about care implies that healthcare users compare their expectations against the actual care delivered and that this leads to either a positive or negative feeling. Hence satisfaction is a result of expectations and actual care experiences. Consequently, variations in satisfaction scores can be a result of differences in either expectations or experiences³, which means ambiguity is an important problem in satisfaction measurement.⁴⁻⁵ In addition, the fact that healthcare users often feel dependant and are grateful to their care providers may result in socially desirable answers and skewed distributions (the majority report being satisfied or very satisfied). Measuring care users' experiences and relating these to their expectations may therefore better reflect the quality of care and may also provide clearer action points for quality improvement purposes.^{3,6,7}

These days, a new generation of quality instruments is available that is based on this approach of measuring actual care experiences.⁸⁻¹¹ This new generation includes the CQ-indices. They have been developed and used for a number of target groups; for example patients who are suspected of having breast cancer, patients with rheumatoid arthritis and patients receiving long-term care.¹²⁻¹⁴ CQ-indices are practical instruments for measuring quality indicators from the care users' perspective.¹⁵ They can provide useful quality information for healthcare organisations, and often also for patients, relatives or external parties such as the Health Care Inspectorate.

In 2007, the Dutch Ministry of Health decided that a CQ-index Palliative Care (CQ-index PC) should be developed that could be used in all settings in which adult patients receive Palliative Care. The development of such a quality instrument is in line with the policy of the Council of Europe,

recommending that “member states, within a consistent health-policy approach for the specific strategy of improving palliative health-care provision, identify practical indicators that can be used to check what progress has been made in patient care over a given period”.¹⁶

The CQ-index PC differs from instruments developed in the past, which ask – often in a traditional, direct way – about satisfaction with palliative care.^{17–22} Moreover, existing instruments often focus on very specific target groups, for example relatives of patients in the final stage of dementia²², persons involved in palliative cancer care²³ or persons in a hospice setting.²⁴ Finally, some existing instruments (e.g.²⁵) are not questionnaires, but semi-structured lists for interviews, and are therefore less appropriate for use in large samples. Thus, the need for a valid questionnaire that could be used to assess the quality of palliative care in various settings prompted the decision to develop a CQ-index PC.

This new instrument consists of a patient version and a version for bereaved relatives. In this paper the focus is on the CQ-index PC version for patients. The details about the version for relatives have been described elsewhere.²⁶

The CQ-index PC combines (1) questions on actual experiences with regard to certain aspects of care and (2) questions about how important respondents find certain care aspects. By relating ‘experience scores’ to ‘importance scores’, insight can be gained in which care aspects should have the highest priority in quality improvement.

This paper aims to present this new approach to measuring patient experiences in palliative care. In particular, it highlights patients’ care experiences, quality aspects to which patients attach high importance, and quality aspects with the highest priority for improvement.

METHODS

Several stages can be distinguished in the development of a CQ-index²⁷, (see Box 3.1): 1. questionnaire construction, 2. assessment of psychometric properties, and 3. assessment of discriminative power. These stages also fit with general approaches in the development of a measurement instrument.²⁸

The discriminative power of the CQ-index PC will be investigated in a future project, and therefore this paper only addresses stages 1 and 2.

Box 3.1 Stages in the development of a Consumer Quality Index

Stage 1. The construction phase, consisting of:

- 1a. Literature study.
- 1b. Focus groups and/or individual interviews.
- 1c. Development of the draft questionnaire, which is tested for face and content validity in a steering committee and/or other expert groups.
- 1d. Pretest, in which the draft questionnaire is tested among a small group of respondents to investigate whether the questions are understandable and complete.

Stage 2. The psychometric test.

The questionnaire is tested among a larger group of respondents. The aim is to shorten the instrument and assess its psychometric properties. Sometimes (like in this paper) the available data are also used to obtain a first impression of the quality of care provided and the care aspects that have the highest priority for improvement.

Stage 3. The test of discriminative power.

The questionnaire is tested among a larger number of respondents to assess whether the instrument is able to detect quality differences over time or between healthcare providers.

Construction of the questionnaire (stage 1)

Literature study

To develop a CQ-index addressing the construct 'the patient perspective on the quality of physical, psychosocial and spiritual aspects of palliative care', first a literature study of existing relevant instruments was performed. No

existing questionnaires were found that were appropriate in every respect for measuring the quality of palliative care from a user perspective in various palliative care settings.²⁶ However, some parts of existing questionnaires (see, e.g.²⁹ provided input for the development of the CQ-index PC.

In addition, relevant studies in which Dutch patients or relatives were asked about crucial elements in the quality of palliative care were studied. In a study by Borgsteede and coauthors, patients considered the following aspects of general practitioner (GP) care crucial at the end of life: the availability of the GP, medical competence and good cooperation with other professionals, attention and the continuity of care.³⁰

The conclusion of this part of the literature study was that different existing studies mentioned different quality aspects of palliative care, but almost all mentioned respect for autonomy, personal attention and privacy.²⁶

Interviews and focus groups

To improve the chance that the instrument has good content validity, we used information from a previous interview study by our research group among 19 patients and 23 relatives.³¹ These interviews focussed on what the patients and relatives thought was important for good palliative care. Various inpatient and outpatient settings were represented in the interviews.

In mid-2008, we conducted additional interviews to refine and validate the earlier interview data. These consisted of three individual interviews with patients, one interview with a relative and one focus group interview with three relatives of patients who had recently died after a long period of illness. In addition, two focus group interviews were held in 2008 with a total of 14 professionals and four voluntary care providers, to investigate important quality aspects further.

Development of the draft questionnaire and testing in the steering committee

The draft questionnaire consisted of 100 items, divided into questions about actual care experiences (experience items), how important certain care aspects are for respondents (importance items) and background characteristics. For each question regarding the patient's experience with a certain aspect of care, a corresponding question was included about how important this care aspect was for the patient.

To reduce recall bias, the experience items mainly concerned the care received in the previous week. Another reason for asking about care experience in the previous week was that many transitions can take place in the palliative phase, and asking about a longer period therefore increases the risk that the patient has difficulty in choosing an appropriate answer. Most of the experience items had answers on a 4-point scale ('never', 'sometimes', 'usually' and 'always', sometimes combined with the option of 'not applicable'). A few experience items had answer options of 'yes' or 'no'.

The importance items all had answers on a 4-point scale ('not important', 'fairly important', 'important' and 'extremely important').

The face validity and content validity of the first version of the CQ-index PC was established in the steering committee, which consisted of 16 experts in the field of palliative care, including care providers, and representatives of patient organisations, national professional organisations and the Ministry of Health.

Pretesting among patients

The completeness and comprehensiveness of the first version was tested in a so-called pretest with nine patients in various palliative care settings. Patients were also asked to respond to some questions about the comprehensiveness and completeness of the questionnaire and the time needed to complete the questionnaire.

The recommendations of the steering committee and the results of the pretest among patients resulted in some minor revisions to the items, for example, changing the answer options for some items to 'yes' or 'no', instead of 'never', 'sometimes', 'usually' and 'always'. This was necessary because some items referred to an experience that could only occur once.

Psychometric test (stage 2)

Sample and data collection

At the end of 2008, the CQ-index PC was tested further among a larger group of patients. Organisations were recruited via existing contacts of the Netherlands Institute for Health Services Research and the EMGO Institute for Health and Care Research. In every organisation there was a central contact person who was responsible for the recruitment of patients. All patients who met the inclusion criteria were approached. Patients were eligible for inclusion if they had a life expectancy of six months or less and/or were receiving palliative treatment. Furthermore, they had to be physically and mentally able to answer the questions in the CQ-Index PC.

Fifteen organisations participated in the measurement of the CQ-index PC for patients; (five high-care hospices, three hospitals, one nursing home, one home for the elderly, four home care organisations and one mental healthcare organisation). The patients were asked to complete the CQ-index PC based on their experiences with care delivered in the previous week by the care institution from which they received the questionnaire.

In inpatient or hospice settings, the CQ-index PC was completed during an interview conducted by one of the researchers or another trained interviewer. Patients at home received the questionnaire by post and had to complete it in writing. The decision to send the questionnaire to these patients by post was made mainly for practical reasons: it was not feasible to visit a large number of patients living at home all over the country within a short time frame and with a limited budget.

Analysis of the psychometric qualities

We aimed to shorten the CQ-index in order to create a manageable instrument. We analysed the distribution of scores, performed item-response analyses, analysed the scores for the importance items and performed Pearson's correlation analyses. Decisions about omitting or reformulating items were largely based on the methodological considerations common in the development of CQ-indexes²⁶ paying critical attention to the items with the characteristics listed in Box 3.2. However, decisions to omit or reformulate items were influenced by the methodological considerations listed in Box 3.2 and by the recommendations of the steering committee and remarks made by respondents.

Box 3.2 Characteristics of items requiring critical attention when shortening a Consumer Quality Index

- * Extremely skewed items (> 90% of answers in extreme category; in extreme category means >90% of the answers in the most positive category ('always' or 'yes') or in the most negative category ('never' or 'no').
- * Items with a high percentage of missing values (>10% missing values) and /or 'not applicable' answers
- * Items with relatively low scores for the associated importance items (if the mean score for an importance item was in the 'bottom 10' of lowest scores)
- * Items with a strong mutual relationship (Pearson's correlation $r > 0.70$)

Analysis of actual care experiences, importance of care aspects and 'need for improvement' scores

Descriptive analyses were carried out of the items asking about actual care experiences, the importance of care aspects and the 'need for improvement' scores.

To obtain an indication of which quality aspects have highest priority for improvement, 'need for improvement' scores were calculated. 'Need for improvement' scores are calculated by multiplying the mean score for a question about the importance of a care aspect by the percentage of respondents with a 'negative experience' with this aspect, and dividing this number by 100. A 'negative experience' means that respondents answered

'never/sometimes' or 'no' to a question about experiences with that aspect of care.

A high 'need for improvement' score means that respondents generally attach considerable importance to a care aspect, but at the same time often have a relatively negative experience. The higher the 'need for improvement' score, the higher the priority for improvement.

Ethics

The research protocol was approved by the Medical Ethics Committee of the VU University Medical Center in Amsterdam. Before inclusion, the patients received verbal and written information about the content and aim of the CQ-index PC, and written informed consent was received from all patients who completed the CQ-index PC in the form of an interview.

RESULTS

Response

There were 133 patients in the 15 organisations participating in the measurements using the patient version of the CQ-index PC who met the inclusion criteria and were given the questionnaire. The net response was 63.9% (n=85).

Over a third of the 85 participants were living at home (n=30, 35.3%); the rest were receiving care in a hospice facility (n=18, 21.2%) or a hospital (n=16, 18.8%), were receiving hospital day care (n=12, 14.1%), were in a nursing home or home for the elderly (n=8, 9.4%) or were in a mental health institution (n=1, 1.2%).

The mean age of the 85 patients was 68, more than half (n=49; 57.6%) were female subjects and the majority (n=75; 88.2%) had cancer. A total of 59 patients (69.4%) completed the CQ-index PC in an interview, and 26 patients (30.6%) completed it in writing.

Psychometric results

The psychometric analyses showed that no items were extremely skewed, and only three items had more than 10% missing values. For 15 items, 10–60% of the respondents had answered 'not applicable'. However, this was not

always a reason for deleting the item because most of these items concerned support from professionals in case of pain or other symptoms; as not all patients suffered from these symptoms, answering 'not applicable' will often be appropriate. Such items were not omitted since the management of pain and other symptoms is a crucial element of palliative care.

There were 10 items with low scores for importance (i.e. a mean score for the importance varying between 2.58 and 3.24). This prompted the decision to omit some of these items (e.g. an item concerning the meals).

There were also some items with strong correlations (Pearson's correlation $r > 0.70$), which was a reason for omission in some but not all cases. For example, the Pearson's correlation coefficient between the item on support when a patient was feeling depressed and the item concerning support when the patient was feeling anxious was 0.92. In this case, neither item was omitted because the strong correlation does not necessarily imply a large overlap in the content of the item.

The foregoing analyses resulted in a reduction in the number of items from 100 items to 88 items (32 experience items, 32 importance items and 24 on background characteristics).

Patients' care experiences

Table 3.1 shows all the experience items, as well as the relatively 'negative' answer categories of 'no' or 'never/sometimes'. The most frequent negative experiences were for the items 'receiving information about the advantages and disadvantages of various types of treatment', 'receiving support when being constipated', and 'receiving support when feeling depressed'. However, a feature of the CQ-index approach is that scores on experience items are related to scores on items about how important care users find certain care aspects in order to gain insight into which care aspects should have the highest priority for quality improvement. In the following sections we therefore discuss the importance scores, and ultimately the 'need for improvement' scores.

Table 3.1 Content and scores of experience items in the Consumer Quality index Palliative Care

Questionnaire section	Experience items (translated from Dutch)	No/never/sometimes n (%)
Care for physical wellbeing	Do you receive support when you are in pain?	15 (17.9)
	Do you receive support when you are tired?	16 (19.5)
	Do you receive support when you have shortness of breath?	13 (16.3)
	Do you receive support when you are constipated?	17 (20.7)
	Do your caregivers help you with your physical self-care?	9 (10.8)
	Do you receive medical aids soon enough?	1 (1.2)
Care for psychosocial well-being	Do you receive support when you feel anxious?	15 (17.9)
	Do you receive support when you feel depressed?	17 (20.2)
	Are your caregivers polite to you?	1 (1.2)
	Do your caregivers listen carefully to you?	3 (3.6)
	Do your caregivers have enough time for you?	6 (7.1)
	Do your caregivers take you seriously?	3 (3.6)
	Do your caregivers show interest in your personal situation?	6 (7.2)

–Table 3.1 continued–

-Table 3.1 continued-

Questionnaire section	Experience items (translated from Dutch)	No/never/sometimes n (%)
	Do your caregivers have a 'warm' attitude?	6 (7.3)
	Do you have the opportunity to talk to your caregivers about how you are feeling?	7 (8.5)
	Do your caregivers pay attention to your relative(s)?	6 (7.3)
Care for spiritual wellbeing	Do your caregivers respect your life stance?	1 (1.2)
	Do you have access to a counsellor for spiritual problems (e.g. a minister/priest or humanist counsellor)?*	
Respecting independence	Do your caregivers give you the chance to plan your own day?	3 (3.6)
	Are you involved in decisions about your care?	5 (6.3)
	Do your caregivers take your personal wishes into account?	3 (3.6)
Respecting privacy	Do you get the opportunity to be alone if you want to be?	6 (8.1)
	Is it possible to talk to someone without being disturbed if you want to?	5 (6.0)
Information	Do your caregivers explain things to you in a way you could understand?	3 (3.7)

-Table 3.1 continued-

-Table 3.1 continued -

Questionnaire section	Experience items (translated from Dutch)	No/never/sometimes n (%)
	Do your caregivers give you contradictory information?*	
	Do you receive information about the expected course of the illness?*	
	Do you know who the contact person is for the care?*	
	Do you receive information about the advantages and disadvantages of various types of treatment?	24 (29.6)
Expertise of caregivers	Do your caregivers have the necessary expertise?	3 (3.6)
	Is there a good match between the care provided by the different caregivers involved in looking after you?	5 (6.1)
	Do you receive help in good time when you are in need of care?	3 (3.7)
	Are you offered help in good time in acute situations?	4 (4.8)

* These items have been reformulated as displayed. Therefore, no numbers or % are presented.

Patients' scores on importance items

The 10 importance items with the highest mean scores are presented in Table 3.2. Patients consider 'help is offered in good time in acute situations', 'caregivers have the necessary expertise' and 'caregivers take you seriously' the most important items.

Table 3.2 Top 10 importance items with the highest mean scores

Item	Mean score for importance item*
Do you think it is important that....	
...help is offered in good time in acute situations	3.80
...your caregivers have the necessary expertise	3.74
...your caregivers take you seriously	3.70
...your caregivers listen carefully to you	3.61
...you receive help in good time when in need of care	3.56
...there is a good match between the care provided by the different caregivers involved in looking after you	3.52
...you receive support when you are in pain	3.51
...your caregivers explain things to you in a way you could understand	3.50
...it is possible to talk to someone without being disturbed if you want to	3.49
...you are involved in decisions about your care	3.49

* These scores varied from 1 (=not important) to 4 (=extremely important).

Quality aspects with 'need for improvement'

Table 3.3 shows the ten aspects that have the highest priority for improvement. The corresponding percentage of negative scores (percentage of respondents who answered 'never', 'sometimes' or 'no') for the experience items and the mean scores for the importance items are also presented in Table 3.3. The items concerning professional support when the patient feels depressed, is anxious or has shortness of breath have the highest 'need for improvement' scores.

Table 3.3 Ten highest ‘need for improvement’ scores with corresponding scores for experience items and importance items.

Item	Need for improvement score	% negative scores for experience item	Mean score for importance item
Support when feeling depressed	1.397	45.95	3.04
Support when feeling anxious	1.354	41.67	3.25
Support when having shortness of breath	1.324	39.39	3.36
Support when constipated	1.145	34.69	3.30
Information about the advantages and disadvantages of various types of treatment	1.031	29.63	3.48
Information about life expectancy*	0.978	36.21	2.70
Support when in pain	0.924	26.32	3.51
Support when feeling tired	0.916	29.63	3.09
Help with physical care	0.486	15.00	3.24
Information about who is the contact person for questions about the treatment	0.433	12.35	3.51

*In the revised version of the CQ-index PC, the ‘Information about life expectancy’ item was reformulated as ‘Information about the expected course of the illness’ because some patients found the initial question too ‘crude’.

The relatively high ‘need for improvement’ scores in Table 3.3 indicate that healthcare providers should give priority to these aspects if they wish to improve palliative care. The scores for the experience items can give healthcare providers more detailed insight into the need for improvement.

For example, the negative experience score of 45.95% for the item about ‘support when feeling depressed’ indicates that almost half of the patients answered that they ‘never’ or ‘sometimes’ received support from care providers when they were feeling depressed. At the same time, the importance score of 3.04 (within a range of 1–4) indicates that patients consider it ‘important’ to ‘extremely important’ that they receive this kind of support. The other ‘need for improvement’ scores in Table 3.3 should be interpreted in the same way.

‘Politeness of the caregivers’, ‘respect for the patient’s life stance’, and ‘receiving medical aids soon enough’ are examples of care aspects with a relatively low priority for quality improvement. The 10 lowest ‘need for improvement’ scores are shown in Table 3.4.

Table 3. 4 Ten lowest ‘need for improvement’ scores, with corresponding scores for experience items and importance items

Item	Need for improvement score	% negative scores for experience item	Mean score for importance item
Politeness of caregivers	0.040	1.20	3.34
Respect for patients’ life stance	0.069	2.33	2.95
Receiving medical aids soon enough	0.071	2.04	3.46
Personal wishes taken into account by caregivers	0.124	3.57	3.46
Receiving understandable explanations by caregivers	0.128	3.66	3.50
Caregivers listening carefully	0.129	3.57	3.61

–Table 3.4 continued–

-Table 3.4 continued-

Item	Need for improvement score	% negative scores for experience item	Mean score for importance item
Receiving help in good time when in need of care	0.132	3.70	3.56
Being taken seriously by caregivers	0.132	3.57	3.70
Expertise of caregivers	0.134	3.57	3.74
Getting the opportunity to plan your own day	0.172	5.66	3.04

There are, of course, also items that are not in the top 10 or in the bottom 10 of the 'need for improvement' scores.

DISCUSSION

The main aim of this paper was to present a new approach and a new questionnaire for measuring patient experiences in palliative care. It highlighted aspects of palliative care to which patients attach high importance and aspects of palliative care that have the highest priority for improvement. This study provides an indication that the questionnaire is suitable for use in various palliative care settings.

To reduce recall bias, most of the items in this questionnaire concerned the care experienced in the previous week. Because respondents had to be physically and mentally able to answer the questions, patients in the terminal phase were excluded. This means that the patient version of the CQ-index PC does not provide insight into the quality of care in the very last days of life. We have therefore also developed a CQ-index questionnaire for bereaved relatives with a specific focus on the care provided in the last week of the patients' life, as well as on support and after-care for the relatives themselves. This questionnaire for relatives has been described in detail elsewhere.²⁶

An important characteristic of the CQ-index PC is that it assesses actual care experiences, not satisfaction with care. Therefore, there will be fewer socially desirable answers than with traditional satisfaction measurements. Two different data collection methods were used. Inpatient and hospice patients were interviewed to complete the CQ-index PC questionnaire, while patients who lived at home received a postal questionnaire. Since only one method of data collection was used in a given setting, no conclusions could be drawn about the impact of different methods of data collection on, for instance, socially desirable answers. This may be further explored in future research.

Another feature of the CQ-index PC is that it covers all aspects of palliative care: physical, social and spiritual well-being. Besides, a distinctive characteristic of this new instrument is that it can be used to gain insight into the patient perspective on which care aspects have the highest priority for quality improvement. In managers' decision making and prioritising of needed quality improvements costs and complexity also will be taken into account. However, in our opinion it is important to look first at the patient perspective, since meeting patients' needs is crucial for high-quality palliative care.

The 'need for improvement' scores in this initial study of the CQ-index PC indicate that support for patients who feel depressed or anxious, or who have shortness of breath are the areas with the highest priority for improvement in the participating Dutch care organisations. However, these organisations were not randomly selected, and the under-representation of some care settings (e.g. homes for the elderly or nursing homes) may have biased the results. Future research with more representative samples will provide more insight into the quality of palliative care and the priorities for quality improvement.

In this initial study, the face validity and content validity of the instrument have been taken into account. At present we are setting up a study with a larger sample for more rigorous psychometric analyses, such as factor analyses and analysis of discriminative power. It would also be interesting to compare different settings and different organisations using a larger sample and to see whether there are differences in quality. For future comparisons, it is also important to gain more insight into the patient characteristics for which statistical adjustments need to be made (case-mix adjustment) in

order to obtain valid comparisons of quality scores. The future research project will provide more insight into these issues.

Conclusions

The CQ-index PC is a new approach to measure the quality of palliative care from the perspective of patients and to determine which care aspects have the highest priority in quality improvement.

At the moment the CQ-index PC has only been tested in Dutch. However, an English translation has been made to inform foreign researchers (available on request). It is recommended that the CQ-Index PC is also tested and validated by researchers in other countries who wish to measure the quality of palliative care from a user perspective and who are interested in priorities for quality improvement.

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Measuring relatives' perspectives on the quality of palliative care: the Consumer Quality Index Palliative Care

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ABSTRACT

Context

A Consumer Quality Index (CQ-index) is a questionnaire assessing the actual care experiences and how important the recipient finds certain care aspects, as well as the priorities for improving quality. A CQ-index Palliative Care (CQ-index PC) for bereaved relatives was developed to measure the quality of palliative care.

Objectives

This paper provides insight into the development and psychometric characteristics of this questionnaire, as well as quality improvement priorities.

Methods

The content of the CQ-index PC was based on existing questionnaires, literature and interviews and focus group discussions with relatives, patients, and caregivers. The questionnaire was tested in 31 care facilities providing palliative care. Close relatives/contact persons of patients who died non-suddenly six weeks to six months earlier were eligible for inclusion. Psychometric analyses were performed to shorten the questionnaire and to assess its reliability. 'Need for improvement scores' also were computed to identify care aspects with the highest priority for quality improvement.

Results

Three hundred ninety-two bereaved relatives were eligible for inclusion. The net response was 52% (n=204). Psychometric analyses resulted in six scales (Cronbach's alphas ranging from 0.71 to 0.90). The quality aspects relatives considered most important were dying peacefully, getting help in good time in acute situations, and personal attention. Aftercare was the aspect with the highest priority for quality improvement.

Conclusion

The CQ-index PC for relatives can be used to assess the quality of palliative care from the perspective of bereaved relatives. This instrument gives health care professionals insight into care aspects with the highest priority for quality improvement.

INTRODUCTION

There is increasing interest in making the quality of palliative care transparent. Transparent information about the quality of care is considered important for health care providers who seek to realize improvements in quality. In addition, information about the quality of care can be used by patients or relatives who want to make a well-founded choice of a health care provider. Furthermore, external parties such as governments and health care inspectorates attach great importance to information about the quality of care from individual health care providers.

Several definitions exist for the quality of care¹⁻³, but most definitions concern two dimensions, namely whether individuals receive the care that they need and whether the care received is effective.¹ Regarding the first, dimension in particular, it is important to gain insight into the user's perspective on the quality of care. As patients are the main target group of health care, they are appropriate persons to judge the quality of care. However, when patients near the end of life, they may no longer be cognitively or physically able to respond to quality questionnaires. Therefore, bereaved family members are also important sources of information about the care received.⁴ They often have a good overview of the care given during the dying phase. Moreover, relatives also can report on the quality of support and aftercare provided to them. This is important since aftercare is a key element in palliative care, as is indeed acknowledged in the World Health Organization definition of palliative care.⁵

In recent years, a variety of measurement instruments for palliative care have been developed dealing with a range of topics.⁶⁻⁸ A systematic review by Hudson et al. described 62 instruments to be completed by the relatives of patients receiving palliative care.⁷ Hudson et al. concluded that the primary focus of existing instruments includes: satisfaction with service delivery (n=14), psychiatric disorders (n=6), quality of life (n=6), needs (n=5), grief and bereavement (n=5), burden (psychological and/or social impact of the carer role; n=4), preparedness/competence (n=3), family functioning (n=3), and other (n=15). Less than half of these 62 instruments were developed specifically for the palliative care context. In addition, existing instruments often focused on a very specific target group, such as relatives of patients with dementia⁹, or on only one specific care setting, such as palliative care at

home.¹⁰ There was no information on the psychometric characteristics of approximately a quarter of the 62 instruments mentioned in the review.

The review by Hudson et al. also shows that instruments administered to family caregivers of palliative care patients often include questions about satisfaction of relatives with the service delivered. A definition of satisfaction is 'fulfilling expectations, needs or desires'.^{11,12} Satisfaction with care, therefore, involves health care users comparing their expectations against the actual care delivered, which leads to either a positive or negative feeling. If health care users have low expectations, they will be more easily satisfied than health care users with high expectations. Satisfaction is, therefore, a result of both expectations and actual care experiences. Consequently, variations in satisfaction scores can result from differences in either expectations or experiences.¹³ This ambiguity is an important problem in satisfaction measurement.^{14,15} In addition, the fact that health care users often feel dependent and grateful to their care providers may result in people giving socially desirable answers, expressed in skewed satisfaction score distributions (the majority reporting 'excellent' or 'good' care).

Measuring the experiences of care users rather than their satisfaction, and relating these to their expectations, therefore, may better reflect the quality of care and also may provide clearer action points for improving the quality.^{13,16,17} To make use of these advantages, a 'new generation' of questionnaires has been developed for measuring care experiences and expectations from the perspective of care users. This new generation includes the Consumer Quality Indices (CQ-indices) for measuring the quality of healthcare in the Netherlands since 2006. The structure of the various indices is largely based on the American questionnaires American Consumer Assessment of Healthcare Providers and Systems questionnaires (CAHPS)¹⁸ and the Dutch Quality Of care Through the patient's Eyes questionnaires (QUOTE).^{13,19}

In the last five years, approximately 23 CQ-indices have been developed for various target groups (see www.centrumklantervaringzorg.nl and^{20,21,22}). CQ-indices are often used to measure 'subjective' quality indicators that reflect the experiences of care users with the care received in a certain care facility or setting. In the Netherlands, these quality indicators are often published on websites or in publications, giving patients and relatives an opportunity to

make a well-founded choice between different health care providers. Besides, CQ-index data can be used to provide transparent accountability information for the Health Care Inspectorate, health care insurers, governmental bodies or other 'third parties'. Data from CQ-indices provide quality information for health care providers seeking to improve the quality of care within their own organizations.

The development of various CQ-indices has been strongly promoted by the Dutch Ministry of Health. In 2008, this Ministry produced a policy document²³, among other things, stating that a CQ-index also was needed in palliative care to improve transparency and encourage improvements in the quality of care.

In response to this, we developed such a CQ-index for palliative care (CQ-index PC). This new instrument, which can be used in various palliative care settings, consists of separate versions for patients and for bereaved relatives. The patients' version is useful for patients who are still physically and cognitively capable of completing this structured questionnaire. However, this implies that dying patients cannot be included as they are no longer physically and cognitively capable. Therefore, there is a separate version for bereaved relatives asking about the quality of palliative care in the last week of the life of the patient and about the quality of support and aftercare for relatives.

This article focuses on the version of the CQ-index PC for relatives. The details of the patients version have been described elsewhere.²⁴ This article aims to present this new instrument for measuring relatives' experiences of palliative care. In particular, it emphasizes the care experiences of relatives in the last week before death of the patient and in the aftercare phase.

In addition, the instrument assesses which quality aspects the relatives find important, and which are the priorities for the improvement of quality.

METHODS

Construction of the questionnaire

The construction phase of a CQ-index always involves several stages²⁵. In the first stage, interviews and/or focus groups discussions are conducted. In the development of the CQ-index PC, our research group had conducted

interviews in a previous study with 19 patients, and 23 relatives provided input for the pilot questionnaire.²⁶ These interviews with relatives and patients focused on what relatives and patients thought as important for good palliative care.²⁶ In mid-2008, one focus group discussion with three relatives, one interview with a relative and two focus group discussions with 18 health care providers were conducted to gather extra data about quality aspects of palliative care that are important for patients and relatives. In addition, three individual interviews with patients were conducted to refine and validate the earlier interview data. We started the focus group discussions and interviews with open-ended questions such as: "Describe some positive and negative care experiences", and "According to you, what makes good quality care?" The focus group discussions were summarized by the researchers in consultation with the participants. The individual interviews were recorded and typed out verbatim. The interviews and focus group discussions were analyzed qualitatively and inductively. The first author (S.J.J.C.) read and reread the material and used inductive coding to categorize the aspects of care that were mentioned as crucial for high-quality palliative care. The process and outcomes of the analysis were discussed by the first author (S.J.J.C.) with the co-authors (A.L.F. and L.D.). Important quality aspects that emerged from the analysis, and which were mentioned frequently in the interviews, were "taking wishes and needs into consideration", "autonomy", "personal/warm attention", "expertise" and "continuity of caregivers".

Another standard element in the process of constructing a CQ-index is a literature study. For the development of the CQ-index PC, relevant literature on existing quality research, CQ-indices, and quality questionnaires were studied.²⁴ No existing questionnaires were found that were completely suitable for measuring the quality of palliative care in various settings and which contained all dimensions of palliative care (physical, psychosocial and spiritual). Some of the items were derived from existing Dutch questionnaires.^{21,27,28}

Furthermore, a steering committee with sixteen experts and stakeholders provided input for constructing the draft questionnaire. The Ministry of Health, national umbrella organizations, health care providers, and representatives of patient organizations were represented in the steering committee. These parties assessed the content validity of the questionnaire

and the comprehensibility of the draft questionnaire. This resulted, for example, in a clearer introduction to the questionnaire.

The first draft of the CQ-index PC for relatives was pre-tested among twelve relatives for comprehensibility and time required to complete the questionnaire, and to check whether questions were missed. This resulted in some minor revisions, for example adding the option “not applicable” to some questions.

Content of the questionnaire

The relatives' version of the CQ-index PC consisted of questions on background characteristics such as age and gender, experience items (questions about actual experiences regarding specific aspects of care), and importance items (questions about how important specific aspects of care are for relatives). It addresses physical, psychosocial and spiritual care aspects.

The questionnaire also contained questions on the support provided for the patient in the last week before death. The reason why we only focused on the week before death is that this is a period in which dying patients themselves will no longer be physically and cognitively able to complete a questionnaire, whereas close relatives often have a very good overview of the care in the period shortly before death. In addition, the questionnaire contained questions on the support provided for the relative in the last week before the patient's death. Finally, questions were asked about aftercare.

The answer categories for most of the experience items were 'never', 'sometimes', 'usually' and 'always' (an ordinal four-point scale), sometimes combined with 'not applicable'. A few experience items had answer options of 'yes' or 'no'. The answer categories for the importance items were 'not important', 'fairly important', 'important' and 'extremely important' (also an ordinal four-point scale).

Sample and recruitment process

The sample consisted of care facilities recruited partly from within the research team's existing professional networks. In addition, care facilities participating in a parallel project on the development of quality indicators²⁹ were invited to participate in this project on the development of the CQ-index PC.

Once a care facility agreed to participate, a central contact person within this facility was assigned. This person was responsible for recruiting all bereaved relatives who met the inclusion criterion of “being a bereaved relative and contact person of a patient who died not suddenly six weeks to six months earlier”.

At the end of 2008, the CQ-index PC version for relatives was sent to 392 bereaved relatives of patients cared for in a total of 31 health care facilities in the Netherlands (five high-care hospices, one low-care hospice, one hospital, five nursing homes, 11 homes for the elderly, six home care organizations, and two mental health care organizations). After two weeks, a reminder was sent to the nonrespondents.

Statistical analysis

Several psychometric analyses were performed to shorten the questionnaire by removing items and to assess the questionnaire’s reliability. The analyses involved calculating the distribution of scores, item–response analyses, calculating scores for the importance items, Pearson’s correlation analyses, factor analysis (principal component analysis with oblique rotation), and calculating Cronbach’s alpha.

When deciding on the items to be removed from the questionnaire, we took account of:

- Extremely skewed items. We considered items extremely skewed if more than 90% of answers were in the most positive category (‘always’ or ‘yes’) or in the most negative category (‘never’ or ‘no’).
- Items with a high percentage of missing values (defined as more than 10% missing values) and/or a high percentage of ‘not applicable’ answers;
- Items with relatively low scores for ‘perceived importance’. A relatively low score is defined as having a mean score for an item on ‘perceived importance’ in the bottom 10 of all the mean scores;
- Items with a strong mutual relationship (Pearson’s correlation $r > 0.70$);
- Items not fitting into scales (according to the factor analysis);
- Items not contributing to the scale reliability (if Cronbach’s alpha < 0.7 and item–total correlation < 0.40).

In addition to the psychometric analyses, the mean scores (for all respondents) were calculated for the importance items. Moreover, ‘need for

improvement' scores were calculated to obtain an initial indication of which quality aspects have the highest priority for improvement. 'Need for improvement' scores are calculated by multiplying the mean score for a question on the importance of a care aspect by the percentage of respondents with a 'negative experience' for this care aspect, and then dividing this number by 100. A negative experience means that a respondent has answered 'never' or 'sometimes' or 'no' to a question about an actual experience with a certain aspect of care. A high 'need for improvement' score means that most respondents attach considerable importance to a care aspect but their experiences of it are often negative. The higher the 'need for improvement' score, the higher the priority an aspect should be given for improvement.

Ethics

The Medical Ethics Committee of the VU University Medical Center in Amsterdam approved this study.

4

RESULTS

Response

Two hundred four of the 392 included bereaved relatives completed the questionnaire (52.0% response). Most respondents were relatives of patients who died at home (27.9%), in a nursing home (27.5%), home for the elderly (17.2%), or relatives of patients receiving care in a hospice facility (23.5%), hospital (1.5%) or mental health care organization (2.5%).

The mean age of the relatives was 60 years; 65% were women. The majority (66%) were relatives of a patient who died of cancer. The biggest group of relatives (45%) were sons or daughters of the deceased patient; 39% were the partner.

Psychometric results

Three items were extremely skewed: the item on "whether the patient had died peacefully", the item on "the politeness of caregivers," and the item on "knowing who is the contact person for treatment."

There were no items that had more than 10% missing values. However, there were three items where about 60% of the relatives had answered 'not

applicable'; these items, therefore, were not included in the subsequent factor analysis.

There were 10 importance items with relatively low scores, varying between 2.33 and 3.23 (within a range of 1 to 4). For instance, an item concerning help with household activities was omitted.

Moreover, some items had strong correlations ($r > 0.70$). This could be a reason for the omission of one of the two correlated items (e.g. the items on information about the life expectancy and information about the approaching death were highly correlated; the first item, therefore, was omitted). However, sometimes highly correlated items were not deleted because, for example, strong correlation does not always imply a large overlap in the content of the item. In addition, arguments and remarks made by relatives in the drafting and testing phase, as well as recommendations of the steering committee, were taken into account when deciding on the omission of items.

Six reliable scales were distinguished based on the factor analyses and reliability analyses. Each scale comprises three or four items. These scales and their items are presented in table 4.1.

Table 4.1 Scales and their reliability scores (Cronbach's alpha)

Scale	Cronbach's alpha	Experience items (Translated from Dutch)
Care for the psychosocial/spiritual well-being of the patient	0.88	Did the caregivers respect your relative's life stance? Were the caregivers accessible for discussions about your relative's approach to the end of life? Did the caregivers pay attention to your relative? Did the caregivers take personal wishes of your relative into account?

-Table 4.1 continued-

-Table 4.1 continued-

Scale	Cronbach's alpha	Experience items (Translated from Dutch)
Care for the relative's own psychosocial/spiritual well-being	0.90	Did the caregivers pay attention to your anxiety? Did the caregivers pay attention to your depression? Did the caregivers respect your life stance? Could you talk to the caregivers about what it meant to care for your sick relative?
Attitude to the relatives	0.81	Were the caregivers polite to you? Did the caregivers listen carefully to you? Did the caregivers have enough time for you? Did the caregivers take you seriously?
Autonomy	0.80	Did the caregivers involve you in decisions about the care for your sick relative? Could you decide what your own task was in the care for your sick relative? Did the caregivers take your personal wishes into account with regard to the care for your relative?
Information for the relative in the last week before death	0.71	Did the caregivers explain things to you in a way that you could understand? Did the caregivers give you contradictory information? Did you receive information about the approaching death? Did you receive information about the options concerning the funeral?
Expertise	0.78	Did the caregivers have the necessary expertise? Was there a good match between the care provided by the different caregivers involved in looking after you? Were you offered help in good time in acute situations?

In addition, eleven stand-alone experience items were distinguished in the questionnaire (see Table 4.2). These items did not fit in a reliable scale. Nevertheless, these items were not removed from the questionnaire because relatives considered them to be 'very important' for palliative care and/or because they scored relatively high as candidates for improvement. In the sections below, we will discuss the scores for importance items and also the 'need for improvement scores'.

Table 4.2 Overview of stand-alone experience items in the questionnaire

<ol style="list-style-type: none">1. Did your relative have access to a counselor for spiritual problems (e.g. a minister/priest or humanist counselor)?2. Did your relative have the opportunity to be alone if he/she wanted to be?3. Did your relative receive support from the caregivers with preparations for saying goodbye to relatives?4. Did your relative accept his/her approaching death?5. Did your relative die peacefully?6. Did you have the opportunity to be alone with your relative if you wanted to be?7. Did you know who the contact person was for the care?8. Did you receive information about the advantages and disadvantages of various types of treatment?9. Did you feel supported by the caregivers immediately after the death of your relative?10. Were you informed about the possibility of aftercare after the death of your relative?11. Was there a final conversation or discussion in which the care and treatment were evaluated?
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Scores for importance items

Table 4.3 lists the five importance items with the highest mean scores. As shown, relatives consider "dying peacefully", "offer of help in good time in acute situations," and "attention" to be the most important.

Table 4.3 Top five items of importance (highest mean scores)

Item Do you think it is important that...	Mean score*	Standard deviation
...people in the last stage of life can die peacefully?	3.87	.391
...help is offered in good time in acute situations?	3.82	.420
...caregivers pay attention to people in the last stage of life?	3.74	.513
...caregivers have the necessary expertise?	3.73	.479
...caregivers take personal wishes into account of people in the last stage of life?	3.73	.477

* These score range was from 1 (=not important) to 4 (=extremely important).



‘Need for improvement’ scores

Table 4.4 shows the five care aspects addressed in the questionnaire that were given the highest priority for improvement. The ‘need for improvement’ score is shown in the left-hand column. This score is obtained by multiplying the figures in the next two columns and dividing the product by 100. The corresponding percentage of respondents who scored experience items negatively by answering ‘never’, ‘sometimes’ or ‘no’ is displayed in the middle column, and the mean scores and standard deviations for the importance items are presented in the right-hand columns.

The items concerning ‘being informed about the possibility of aftercare’, a ‘final conversation or discussion in which the care and treatment were evaluated,’ and ‘receiving information about options concerning the funeral’ have the highest ‘need for improvement’ scores.

Table 4.4 Five highest 'need for improvement' scores with corresponding scores for experience items and importance items.

Item about:	'Need for improvement' score	% with negative score for experience item	Mean score for importance item	Standard deviation for importance item
being informed about the possibility of aftercare after the death of the relative	1.597	58.3	2.74	0.935
final conversation or discussion in which the care and treatment are evaluated with the relative	1.444	53.1	2.72	1.020
receiving information about options concerning the funeral	1.275	48.1	2.65	1.085
receiving support with preparations for saying goodbye to the relative	0.837	24.2	3.46	0.701
receiving information about the approaching death	0.763	21.2	3.60	0.638

The relatively high 'need for improvement' scores in Table 4.4 indicate that health care providers should prioritize these aspects if they want to improve palliative care. For example, 'being informed about the possibilities of aftercare' has a 'need for improvement score' of 1.597 with a 58.3% negative score for the experience item and a mean score of 2.74 for the importance item. This score indicates that more than half of the bereaved relatives (58.3%) answered that they were not informed about this (the answer options were 'yes' or 'no').

The importance score of 2.74 (in a range from 1 to 4) indicates that relatives consider it 'fairly important' to 'important' that they are informed about the possibilities of aftercare.

DISCUSSION

This article shows that the CQ-index PC for relatives is an instrument that contains six reliable scales addressing the quality of palliative care. The CQ-index PC for relatives contains questions about the care for the patient in the last week of life and about the support for relatives in this final week before death. It addresses physical, psychosocial, and spiritual care aspects. In addition, aftercare for relatives is an important aspect of the CQ-index PC for relatives.

A key characteristic of the CQ-index PC is that the instrument asks about actual care experiences, whereas most other quality instruments addressing the user perspective directly ask about satisfaction^{7,28}, with a higher risk of getting socially desirable and skewed answers. Although there are a few other instruments addressing actual experiences of palliative care (for instance the toolkit)³⁰, the CQ-index PC differs from these instruments, as it also includes items addressing how important respondents find certain care aspects. This means that the importance that patients and relatives attach to certain quality aspects can be taken into account when quality improvements are planned. For example, if a care user has a bad experience with a certain quality aspect but does not find this quality aspect very important, this is less crucial than when care users have bad experiences with a quality aspect they consider extremely important. Combining actual care experiences with importance scores produces 'need for improvement' scores. If professionals want to improve the quality of their palliative care, they should focus on the highest 'need for improvement' scores. In this study, it turned out that aftercare had the highest 'need for improvement' as reflected in the scores for the aspects 'being informed about the possibilities of aftercare' and 'final conversation or discussion in which the care and treatment were evaluated.'

Because aftercare has the highest priority for improvement, health care providers should be made aware of the importance of aftercare, for example, through training and clinical supervision. In addition, managers in palliative

care have the responsibility to arrange satisfactory provision of aftercare for the closest relatives.

To gain a complete picture on the quality of palliative care within a specific care facility, the patients' version of the CQ-index PC²⁴ must also be used, besides the version for bereaved relatives. Some questions in the relatives' version correspond to questions in the patients' version (e.g. an item concerning the expertise of caregivers and an item concerning respect for the patient's life stance). Asking bereaved relatives about their perspectives on the quality of palliative care will always be valuable, even when the patients themselves are able to complete the patients' version of the questionnaire. Bereaved relatives are particularly appropriate respondents for questions on the final period as they have a good overview of the care in the very last days of the patient, and can provide information on the aftercare they themselves have received.

As already stated in the introduction, CQ-indices may be used for several purposes and also may function as a practical instrument for measuring quality indicators from the care users' perspective.²⁹ Internationally, there is an increasing interest in quality indicators in palliative care.^{31,32} Some quality indicators can be relatively 'objective' in nature, such as the percentage of patients suffering from specific problems or symptoms in the palliative phase^{29,31}, whereas other quality indicators reflect care users' subjective appraisals of the quality of care. CQ-indices are appropriate instruments for measuring the latter type of quality indicators.²⁹

One limitation is that no items about care for the physical well-being of the patient were included in the CQ-index PC for relatives. This was a deliberate choice, as relatives do not always know what specific interventions there have been to relieve pain and other physical suffering. However, this aspect is covered in depth in the patients' version of the CQ-index PC. Moreover, in a parallel project, we developed several quality indicators addressing physical symptoms, measured using numerical rating scales.²⁹ These quality indicators concern the percentages of patients with (moderate to severe) pain, constipation, fatigue and shortness of breath. We recommend, therefore, also measuring these kinds of more 'objective' quality indicators in addition to measurements of 'subjective' experience with the CQ-index PC.

In the study presented, we used the CQ-index PC in various palliative care settings such as the patient's home, hospice facilities, nursing homes, homes for the elderly, hospitals, and mental health institutes. However, the ability of the CQ-index PC to discriminate between settings has not yet been determined. Future research will shed light on whether the CQ-index PC can detect quality differences over time or between health care organizations, for example with regard to aftercare. Some care facilities, particularly hospices, have a longer tradition of specialized palliative care than others. Hence aftercare, for example, might be expected to be a regular part of the care given in hospices but not necessarily in general hospitals. We are currently preparing a study with larger samples, which will enable comparisons between settings and the testing of such hypotheses.

At the end of this development process, a CQ-index PC for relatives is now available to obtain insights into the quality of palliative care from the perspective of bereaved relatives. This questionnaire differs from other quality instruments in palliative care because it examines relatives' actual care experiences as well the importance relatives attach to various care aspects. Combining actual experiences with importance scores allows priorities for quality improvement to be established.

At the moment, the CQ-index PC has only been tested in Dutch. However, an English translation has been produced for informational purposes for foreign researchers (available on request). It is recommended that the CQ-Index PC also should be tested and validated by researchers in other countries who want to measure the quality of palliative care from a user perspective and who are interested in priorities for quality improvement.

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Part II

The palliative care continuum



*How do GPs identify a need for palliative care in their patients?
An interview study*

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Submitted

ABSTRACT

Background

Little is known about how GPs determine whether and when patients need palliative care. Little research has been done regarding the assumption underpinning Lynn and Adamson's model that palliative care may start early in the course of the disease. This study was conducted to explore how GPs identify a need for palliative care in patients with cancer or other chronic diseases and in frail elderly.

Methods

A qualitative interview study was performed among 20 GPs in the Netherlands.

Results

GPs reported that a combination of several signals, often subtle, made them identify a need for palliative care: signals from patients (increasing care dependency and not recuperating after intercurrent diseases) and signals from relatives or reports from medical specialists. GPs reported differences in how they identified a need for palliative care in cancer patients versus those with other diseases. In cancer patients, the need for palliative care was often relatively clear because of a relatively strict demarcation between the curative and palliative phase. However, in patients with e.g. COPD or in frail elderly, GPs' awareness of palliative care needs often arises gradually, relatively late in the disease trajectory. GPs consider the diagnosis of a life-threatening illness as a key point in the disease trajectory. However, this does not automatically mean that a patient needs palliative care at that point.

Conclusions

GPs recognize a need for palliative care on the basis of various signals. They do not support the idea underlying Lynn and Adamson's model that palliative care always starts early in the course of the disease.

BACKGROUND

Today, relevant policy makers and other experts are increasingly aware that palliative care is a broader concept than terminal care. In 2003, a 'model' of palliative care was introduced by Lynn and Adamson¹ that underlined the necessity of an early start of palliative care. Initially, curative, disease-modifying and life-prolonging treatments may be given alongside palliative treatments, with a gradual shift to an emphasis on palliation. However, previous studies in Belgium and the Netherlands indicated that in practice the shift from curative and life-prolonging treatments towards palliation often occurs at a late stage in the disease trajectory^{2,3}, suggesting that sometimes GPs or other relevant professionals only recognize patients' need for palliative care late in the disease trajectory.

Nowadays there is also an increasing awareness that palliative care is not only for patients with incurable cancer but also for patients with COPD, heart failure or dementia, for instance. GPs' recognition of a need for palliative care may be different for cancer patients than for patients with other diseases since disease trajectories vary.^{4,5} Lynn and Adamson have described three common disease trajectories.¹ First, there is a trajectory often seen in cancer patients, characterized by a relatively short period of evident decline, a rather clear demarcation between the curative and palliative stages and a foreseen death. In contrast, the disease trajectory of patients with heart failure or COPD is often characterized by long-term limitations, intermittent exacerbations and remissions, resulting in a relatively sudden death. In frail elderly there is often a prolonged gradual deterioration towards death. Various disease trajectories can therefore be distinguished that may be related to variations in the timing and nature of the recognition of a patient's need for palliative care. However, few studies have been conducted to date on GPs' recognition of their patients' need for palliative care.⁶

The scarcity of research literature on GPs' recognition of a need for palliative care is remarkable, since GPs often have a long 'history' with the patient and family and also play a pivotal role in palliative care. In the Netherlands, for example, palliative care is mainly provided by 'general' health care professionals, like the GP and home care professionals, to guarantee that this care is accessible for everyone who is in need of it. Hence, palliative care is integrated into the regular healthcare system, in which GPs function as

gatekeepers for specialized care services and as family doctors.

Considering GPs' pivotal role in palliative care this qualitative study was conducted to explore how GPs recognize a need for palliative care in various patient groups.

The specific research questions addressed in this paper are:

1. How do GPs recognize a need for palliative care?
2. Does this recognition generally arise in the diagnosis stage or in later stages of the disease trajectory?
3. Are there any differences in the timing and nature of GPs' recognition of the need for palliative care between:
 - a. cancer patients;
 - b. patients with other chronic diseases, for example heart failure or COPD;
 - c. frail elderly?

METHODS

Sample and recruitment

GPs were recruited in several ways. First, GPs who had participated in a previous survey about palliative care in general practice had been asked whether they were also willing to be interviewed. Secondly, GPs were recruited by 'snowball sampling' and via the researchers' personal networks. Purposive sampling was conducted to guarantee variation in background characteristics such as age, gender, experiences with palliative care, degree of urbanization and kind of practice.

Recruitment of GPs stopped after data saturation was reached (i.e. no additional themes relevant for answering the research questions emerged during additional interviews and subsequent data analysis).

Ethical procedures

According to Dutch law, approval by a medical ethics committee is not needed for non-experimental interview data involving competent adults. The anonymity of the GPs was strictly preserved throughout the data entry and analysis process. All GPs were given verbal and written information about the aim and scope of the interviews and all GPs gave written informed consent.

Interviews

The interviews were semi-structured with a topic list. The topics included the GP's own definition of palliative care, and their recognition of the need for palliative care in cancer and other patients. The main interview questions related to these topics were: "Can you describe your patients who currently receive palliative care and the care you give them", and "How did you recognize that these patients had a need for palliative care?"

The interviews were audio taped, transcribed verbatim and rendered anonymous.

Analysis

As usual in qualitative research, data analysis started after the initial interviews were conducted as part of a cyclical process of data collection - data analysis - new data collection, et cetera.

The first author (SC) analyzed all the interview transcriptions, while the second author (ALF) analyzed half of the interviews. Both authors independently summarized their individual analyses in 'memos' describing important findings from each interview. These memos were compared, and any apparent disparities were discussed until agreement was reached.

In addition, the interview transcripts were systematically coded by the first author, initially by 'open coding' of text fragments. Open coding is the stage in the analysis concerned with identifying, naming and categorizing phenomena found in the text. Subsequently, 'axial coding' was done. Axial coding involves looking for connections between categories of codes. Ultimately, 'selective coding' took place: one core concept (viz. subtle signals from patients) was determined and related to other categories. The coding process was supported by the Atlas.ti program.⁷ This software program sorts relevant fragments and links these to other fragments with the same codes within a single interview and in other interviews. Results of the interim and final analyses were reported and discussed during meetings with the other co-authors.

RESULTS

Participating GPs

We conducted qualitative interviews with ten male and ten female GPs between spring 2011 and spring 2012. Mean interview duration was about 50 minutes. Mean age of the GPs was 48 years (range of 30 – 62). GPs on average worked 38 hours a week (range 20 – 60). There was a mix of GPs working in group practices (n= 17) and in one-person practices (n= 3). The practice location areas ranged from highly urbanized regions (n= 11), slightly urbanized (n= 5) and less urban/rural regions (n= 4).

INTERVIEW RESULTS

GPs' views on the start of palliative care

GPs mainly associate palliative care with a relatively circumscribed period of a few weeks or months in which incurably ill people need a great deal of physical, psychosocial and spiritual care. Some GPs add that they realize palliative care may start years before death in the case of certain chronic diseases such as COPD or heart failure. However, the immediate association is still with a limited period at the end of life in which the patient (and often their close relatives) make increasing demands on the GP, care needs become more intensive, and contacts become more frequent.

(GP 10, male): Well, I think my feeling is that the palliative phase starts when the care needs start to get more intensive. So when you notice that contact isn't just once every three months... just asking hey, how's it going, if that shifts to more intensive care, where your help is demanded on a more regular basis or where you feel perhaps I should pop in more often to keep an eye on things, to my mind that is a kind of start to the palliative phase.

While GPs do see palliative care as more than just terminal care, and some are clearly familiar with Lynn and Adamson's model (see introduction), that is not sufficient reason for them to start using the term palliative care right from the moment of diagnosis. Nevertheless, GPs do see the diagnosis phase as an important phase, and they offer support to the patient and relatives to cope with the diagnosis. However, GPs feel there is little to be gained from seeing this as the start of palliative care, especially as many people with cancer, for example, will eventually recover. Patients are often not yet dependent on healthcare in the early stage of a life-threatening disease, and

in such situations GPs feel it does not make sense to talk of 'palliative care'.

(GP 19, female) Well yes... if it really is about people with COPD or people with heart failure and so on – and I think these are mainly the people we are talking about, or people with muscular conditions – even though you know someone is eventually going to die from this there is a long period before dying, you can say it's really a chronic disease. You know they will eventually die from it. I find it difficult to say whether you should call that entire period palliative care. Well... as I said, well we discussed it earlier when I said that I'm not thinking about that, I don't start offering different care because it's suddenly called palliative care or chronic care. Because you always try just to make things as comfortable as possible for the patient. So perhaps the label applied to it is just not so important. That's my feeling... why should you call it that?

It is often not the diagnosis but a combination of generally subtle signals that prompts GPs to consider palliative care needs. These signs come initially from the patient, frequently in combination with reports by other care professionals and close relatives. We explain the different signs below.

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Subtle signals given by patient

Changes in self-care abilities and care dependency

The recognition of a need for palliative care is often a gradual process steered by a combination of signals. One key signal is a reduction in a patient's self-care ability, in the sense that it costs a patient an increasing amount of effort to look after himself. Often, a patient also becomes increasingly bedridden and dependent on care by relatives and professionals. The care needs addressed to the GP also become more frequent and more intense. A patient who always used to come to the GP practice may suddenly request a home visit. Two GPs describe increasing healthcare demands in the interview excerpts below.

(GP 3, male): 'It starts when the care need increases.

Interviewer: Could you explain that?

Well, as a patient you obviously try to keep to your old lifestyle as much as possible. And if you have to give that up and ask for help because you can no longer manage to eat or sleep or because of the pain, that is the point when

you can give a patient support.'

(GP 1, female): 'Yes, there are different kinds of palliative care. And the real palliative care is the final stage as it were, because then more care is needed from the people around them or from outside. And if someone becomes progressively dependent on others. I think that this... is so for various activities of daily living, that they can no longer do themselves.'

Not recuperating

Not recuperating fully after an additional condition, such as bladder infection, is also a signal for GPs that they need to monitor this patient particularly closely. Normally people should be back to normal, but the anticipated recovery never happens or is only partial, and this is a signal for GPs that their patients are 'sliding' into the palliative phase.

(GP 4, female): 'These are people who sometimes don't recuperate after a particular condition as you expect – hey, I treated that bladder inflammation and... so it is partly a case of expectations and knowing that if I treat that condition they should recuperate after a certain period. Then someone should be back to normal, but look, they're not. And that's often the start.'

Social changes

Social changes are also a signal for GPs that there is a need for palliative care, for example if people become withdrawn, less focused on contacts beyond their close relatives and no longer get pleasure from hobbies or going out. Life becomes more 'existential' in the sense that they concentrate on the people and things that are most important to them, and focus on closure and taking leave of life.

Signals from close relatives

GPs also often get signals from close relatives. A partner or other close family member will often report deterioration in the patient's situation or say that the burden of care is becoming very heavy and that they need to discuss matters.

(GP 9, male): 'Yes, or the family carers for example. They may well be the biggest source. You see the family carer, who often ends up dealing with

most of the demands for help and care, and they say, well, I'm finding it a bit too much, I'm finding the going too tough, I need someone I can discuss things with now and then. And you see the family carers are often just as pleased with a GP who visits regularly as the patients themselves are. So they also play an important part.'

Reports by other professionals

Another signal for GPs that a patient may require palliative care is a message from the medical specialist that cure is not, or no longer, a possibility. This is also the point at which the medical specialist refers the patient back to their GP, who once again becomes the primary treating physician.

Interviewer: 'If you now think more generally about patients who require palliative care, how do you recognize their need for that care?

(GP 3, male): The need that arises or comes automatically if people are discharged from hospital or if they say there is nothing more we can do for you. That's really when it begins...'

The home care organization may also sound the alarm. For instance, the district nurse may phone the GP to say there are problems with the patient, the family is overburdened and something needs to be done. A signal like that in combination with other signals alerts a GP and makes them feel there is a need for palliative care.

Differences in recognition of palliative needs for different conditions

GPs mention differences in the recognition of a need for palliative care depending on the conditions people are suffering from. There is often a relatively clear demarcation between the curative and palliative phases for cancer patients, as a medical specialist will say curative treatment is no longer possible. An additional factor is that the diagnosis of cancer is often experienced as a 'bombshell' by the patient, their close relatives and sometimes even the GP. Even if GPs feel that palliative care does not automatically start with the diagnosis, in the case of cancer everyone is aware of the real chance that the patient will die. As a result, the option of palliative care is on top of mind at an earlier stage than is the case for many chronic diseases.

(GP 10, male): 'Usually it's the case that as soon as they have had the diagnosis, people start to think this could well mean I die and I am still so young. Or fine, I've had a good life, I have to die of something... but at any rate they'll be aware they might die when they get the diagnosis. So that's a totally different process. So I feel these people often... of course they sometimes also get the shock of seeming to have completely recovered and then they collapse again. But of course often people... the attempts at a cure don't work out and they gradually get reconciled to the idea. And then it's a very clear process, then they are thinking about it. And for you as a doctor... these are very intensive things... but I do think there is a certain clarity.'

GPs explain that it is often more difficult to predict how other chronic, ultimately terminal conditions will progress compared with cancer. People with COPD, heart failure or Parkinsonism are often still being treated by a medical specialist in the final stages. They do not have a clear point where the medical specialist says there are no more treatment options. In the excerpt below, a GP explains how he often gradually becomes aware of a need for palliative care.

(GP 9, male): 'Well, as I said, it is relatively somewhat easier with cancer patients because then you often get a message from the hospital that the curative treatment has failed, so then you know that from that moment on these people are officially palliative. Although certainly at first we often don't get that involved. And in the case of COPD or heart failure and so on it's more of a question of noticing at a particular point, well, we seem to be doing palliative things, without it being an explicit decision, but more that you... yes, there comes a point where the policy gradually changes... and there comes a point when you realize, yes, we really are giving palliative care.'

GP also often have the feeling with frail elderly patients who eventually die following a general physical and cognitive decline that patients slowly, gradually veer off into 'a palliative process'. They describe this as a natural development, the 'circle of life'. A GP explains:

(GP 8, male): But after they get to 85 or so, lots of people are finished with life, or no longer see it as a real... yes, as a diversion that they are going to die or that it is coming to an end. They're finished with life, so dying is a very

natural thing. And then you don't have so much of an explicit feeling of now we are going to opt for palliative care.'

DISCUSSION

Summary of main findings

GPs recognize a need for palliative care on the basis of various, often subtle signals. An important signal is a rise in a patient's care dependency, in the sense of an increasing need for help in daily functioning and a growing reliance on family members and professionals. In addition, not recovering after intercurrent diseases may be a signal that there is a need for palliative care. These signals are often accompanied by reports by family members, home care professionals and medical specialists. Thus, GPs take into account the patients' context and environment when recognizing palliative care needs.

We found differences between recognizing palliative care needs among patients with cancer, patients with other chronic diseases and the frail elderly. In cancer patients, the demarcation between the curative and palliative phases is often relatively clear for GPs. In the case of these patients, the medical specialist informs the GP when curative treatments are not an option or have been stopped. Then the patient is referred from the medical specialist to the GP and a palliative care policy is started. This makes it relatively easy for GPs to demarcate the need for palliative care. However, in patients with chronic diseases such as COPD and heart failure, the course of the disease is often less predictable and patients continue to be treated both by a medical specialist in the hospital and their GP. Consequently, recognition of the need for palliative care often arises gradually. Furthermore, in the case of frail elderly where physical and cognitive functions deteriorate steadily, GPs experience the gradual decline as the normal course of life. Therefore, recognition of the need for palliative care also arises gradually.

Currently, experts like Lynn and Adamson consider the palliative phase as a care continuum which starts early in the course of a life-threatening illness.^{1,8} Dutch GPs also consider the diagnosis stage as an important stage in the patient's disease trajectory. However, they do not necessarily see the

diagnosis as the starting point for palliative care. Although GPs may give support at the time of the diagnosis, they do not call it palliative care as long as cure is still a possibility or as long as patients are not care-dependent. They see no added value in talking about 'palliative care' when cure is still an option or when the patient does not need much care.

In line with Lynn and Adamson¹, Fitzsimons et al. pointed to the necessity of embracing the palliative care approach at an early stage in order to address the needs of patients with life-threatening chronic illnesses.⁹ Our findings indicate that Dutch GPs have a somewhat different view and that they do not think that palliative care always starts early in the disease trajectory. They identify the need for palliative care on the basis of a variety of often subtle signals from the patient, combined with signals from relatives and other professionals. GPs do give support around the diagnosis, but they do not want to designate this as palliative care. Some of them also indicated that the word 'palliative' in communication with a patient who is still living life to the full, is also not a very useful term.

Strengths and limitations

So far, little empirical research had been conducted regarding the assumption that palliative care should start early in the course of the disease. Our research seeks to close this gap. Most previous palliative care research has focused exclusively on patients with cancer.¹⁰⁻¹² A strength of this study is that it also focuses on GPs' experiences with other (growing) patient groups, such as the frail elderly and people with chronic non-cancerous diseases. This study was based on qualitative interviews. Qualitative interviews provide 'rich' detailed data on subjective experiences and views. Qualitative methods are recommended when research topics are relatively unexplored and no structured measurement instruments are available, as was the case in our study. However, qualitative designs have limitations regarding generalizability and the external validity of the findings.

Implications for research and practice

Future quantitative research is recommended in which the hypotheses derived from this qualitative study are tested with a larger group of GPs. This would provide a more complete and generalizable picture of the recognition by GPs of the need for palliative care. In addition, it would be interesting to combine and compare multiple perspectives in a future study: those of the

patients, the family members, the GPs and of other professional caregivers.

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 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 patients¹³, 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.

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Important treatment aims at the end of life: a nationwide study among GPs

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ABSTRACT

Background

Little is known about treatment aims during the last 3 months of life.

Aim

To investigate important treatment aims in the last 3 months of patients' lives in cases of non-sudden death.

Design and setting

Mortality follow-back study in the Netherlands.

Method

Data were collected retrospectively in 2009 within the representative Sentinel Network of GPs in the Netherlands. GPs completed a standardised registration form.

Results

Data for 279 patients were studied. Of these, 55% died of cancer and 45% of another disease. Treatment was aimed at palliation for 73% of the patients in months 2 and 3 before death, and for 95% of the patients in the last week of life. Seven per cent received treatment aimed at cure in the last week of life. In a minority of patients, cure/life prolongation and palliation were simultaneously important treatment aims. In the last week of life and in the 2–4 weeks before death, cure was more frequently reported as an important treatment aim in patients with a non-cancer disease than in patients with cancer. In the 2–4 weeks before death, palliation was an important treatment aim for a larger proportion of patients with cancer than patients with other diseases.

Conclusion

Registration by GPs show that, in the last weeks and days of life, cure was more frequently reported as an important treatment aim in patients with a non-cancer disease than in patients with cancer. For a small number of patients, palliation and cure/life prolongation were simultaneously important treatment aims.

INTRODUCTION

The World Health Organization defines palliative care as:

'An approach that improves the quality of life of patients and their families facing the problems associated with life-threatening illness, through the prevention and relief of suffering by means of early identification and impeccable assessment and treatment of pain and other problems, physical, psychosocial and spiritual'.¹

Lynn and Adamson developed a model for palliative care that builds partially on this definition.² According to this model, the palliative phase starts with the diagnosis of a disease that will probably lead to death. Initially, curative and life-prolonging treatments may be given alongside palliative treatments. According to this model, the emphasis on curative/life-prolonging treatments decreases gradually, shifting to an emphasis on palliation. However, few empirical data exist on the timing of this transition and the possible coexistence of treatment aims.

This study explores important treatment aims in the last 3 months of life for cancer patients versus non-cancer patients, and how these treatment aims may change as death approaches. To date, the main focus of attention of palliative care research has been on patients with cancer. However, there are indications that the disease symptoms often fluctuate in patients with non-cancer illnesses, such as end-stage chronic obstructive pulmonary disease (COPD) or heart failure, and the course of the disease is therefore difficult to predict.³⁻⁵ It can be expected that the shift towards palliative care in these patients may only take place shortly before death and that identifying a time point for transition to palliative care is more difficult for people with COPD, for instance.⁶ The course of the disease in patients with incurable cancer maybe relatively predictable, with a clearer demarcation between the curative and palliative stages.^{3,7}

Little research has been done to test the assumption that palliative care may be started in an early stage, alongside curative or life-prolonging treatments. Van den Block et al found that the transition from cure to palliation often occurs at a late stage, and sometimes not at all.⁸ They also found substantially higher odds of palliative treatment goals for cancer patients in the last 3 months of life than for patients with another cause of death.⁸

However, in general, very limited research has been conducted into the differences between cancer and non-cancer patients, with regard to treatment aims at the end-of-life stage.⁹

The following research questions will be addressed using registration data of Dutch GPs:^{8,10-12}

1. What were important treatment aims for patients who died non-suddenly in (a) months 2 and 3 before death, (b) 2-4 weeks before death, and (c) the last week of life?
2. Was there a coexistence of important treatment aims; that is, were cure/life prolongation and palliation considered important at the same time?
3. Are there any differences between patients who died of cancer and patients with another non-sudden cause of death, regarding important treatment aims in the last 3 months before death?

How this fits in

Previous research in Belgium provided indications that a transition from cure to palliation often occurs late in the illness trajectory and sometimes not at all. The study presented shows that in the last 3 months of life there is an increase in treatments aimed at palliation, while there is a decrease in curative or life-prolonging treatments. In the last month, and also in the last week of life, cure is still an important treatment aim in some patients, although this is more often the case in patients with a non-cancer disease than in patients with cancer.

METHOD

Study design and sample

Data were collected within the Dutch Sentinel Network of General Practices. In 2009, this consisted of 41 general practices (58 GPs), covering 0.8% of the 16 million patients in the Netherlands.¹³ This network is representative of all GPs with regard to age, sex, and population density.

GPs filled in a registration form after the death of each patient older than 1 year of age. In the Netherlands, in principle, all residents have a personal GP.

The GP has a central role in the delivery of palliative care for people dying at home or in a home for older people. For this study, the following inclusion criteria were used:

- the patient's death was expected and non-sudden, as judged by the GP; and
- in the final year before death, the patient resided either at home or in a home for older people.

Data of nursing-home residents were excluded because nursing-home physicians rather than GPs have the main responsibility for the end-of-life care of these patients in the Netherlands.¹⁴

Instrument

The instrument is a standardised 21-item registration form. This form was first tested for comprehensibility by GPs and consisted of multiple-choice and open-ended questions.

Important treatment aims were registered by asking: 'How important were the following aspects of patient care: treatment aimed at cure?; treatment aimed at life prolongation?; and treatment aimed at palliation?' GPs had to register these treatment aims retrospectively for the last week of life, the 2-4 weeks before death, and months 2 and 3 before death, using a 5-point Likert scale ranging from 1 (not at all important) to 5 (very important). Multiple responses (that is, treatment aims) were possible in each period.

Statistical analysis

The following approach was used to analyse the coexistence of important treatment aims: there is coexistence when the GP scored 4 or 5 for treatment aimed at palliation in combination with a score of 4 or 5 for treatments aimed at cure and/or life-prolongation. This analysis was done for each of the three different time periods.

To analyse differences between patients who died of cancer and patients with another cause of death, χ^2 analysis' was performed (SPSS, version 15.0). The scores on the item 'How important were the following aspects of patient care?' were dichotomised by combining the scores 1, 2, and 3, and by combining scores 4 and 5. Differences between the two groups of patients (cancer versus non-cancer) regarding treatment aims were tested for the three time periods distinguished.

Ethical approval

According to Dutch law, no approval of a medical ethics committee is needed for post-mortem anonymous data. The anonymity of the patients and GPs was strictly preserved throughout the data-entry and analysis process.

RESULTS

Study population

The GPs reported 495 deaths in a 1-year period in 2009. Sixty-one per cent (n = 279) of the deaths were non-sudden. Results are based on data of 279 patients with a non-sudden death (Table 6.1).

Eighty-two per cent of the patients were aged ≥ 65 years. More than half of the causes of death were malignancies; 63% of the patients died at home or in a care home, and 26% of the patients died in a hospital.

Table 6.1 Patient characteristics for non-sudden deaths (n=279).

Characteristic	Cancer, n= 153	Non-cancer, n (%)=126 ^a	Total n=279
Age at death, years			
1-64	43 (28.1)	8 (6.3)	51 (18.3)
65-84	91 (59.5)	49 (38.9)	140 (50.2)
≥ 85	19 (12.4)	69 (54.8)	88 (31.5)
Sex			
Male	71 (46.4)	44 (34.9)	115 (41.2)
Female	82 (53.6)	82 (65.1)	164 (58.8)
Place of death			
Home	84 (54.9)	38 (30.2)	122 (43.7)
Care home	14 (9.2)	41 (32.5)	55 (19.7)
Hospital	28 (18.3)	44 (34.9)	72 (25.8)
Palliative care unit/hospice	27 (17.6)	3 (2.4)	30 (10.8)

^a Cardiovascular diseases (12.9 %); Respiratory diseases (7.9%); Diseases of the nervous system (2.9%); Stroke (3.9%), Old age (11.8%); Other (5.6%).

Important treatment aims

Important treatment aims in the three time periods studied are presented in Table 6.2.

Table 6.2 Importance of treatment aims in three time periods: months 2 and 3 before death, the 2–4 weeks before death, and the last week of life (n=279).

Scores on Likert scale	Treatment aims, n (%)		
	Cure	Life prolongation	Palliation
Months 2 and 3 before death			
1 (not at all important)	115 (54.2)	90 (42.7)	16 (7.3)
2	26 (12.3)	31 (14.7)	11 (5.0)
3	24 (11.3)	38 (18.0)	31 (14.2)
4	21 (9.9)	26 (12.3)	40 (18.3)
5 (very important)	26 (12.3)	26 (12.3)	120 (55.0)
2–4 weeks before death			
1 (not at all important)	158 (70.2)	123 (55.7)	5 (2.2)
2	23 (10.2)	29 (13.1)	7 (3.0)
3	20 (8.9)	29 (13.1)	14 (6.1)
4	14 (6.2)	21 (9.5)	45 (19.5)
5 (very important)	10 (4.4)	19 (8.6)	160 (69.3)
Last week of life			
1 (not at all important)	200 (85.1)	183 (78.2)	8 (3.3)
2	9 (3.8)	15 (6.4)	1 (0.4)
3	9 (3.8)	15 (6.4)	4 (1.6)
4	7 (3.0)	11 (4.7)	27 (11.0)
5 (very important)	10 (4.3)	10 (4.3)	206 (83.7)

Palliation was an important treatment aim in 73% of the patients in months 2 and 3 before death, increasing to 89% in the 2–4 weeks before death, and 95% in the last week of life.

Life prolongation became less important as death neared. Life prolongation was an important treatment aim in 25% of the patients in months 2 and 3 before death, in 18% in the 2–4 weeks, and in 9% of patients in the last week before death.

In addition, GPs reported that treatments aimed at cure were important in 22% of the patients in months 2 and 3 before death, in 11 % in the 2–4 weeks before death, and in 7% in the last week of life.

Figures 6.1 and 2 show important treatment aims for patients who died of cancer and for patients with another cause of death. These figures are based on the data of GPs who responded with a score of 4 or 5 for the question ‘How important were the following aspects of patient care?’.

Figure 6.1 Important treatment aims for patients with cancer.

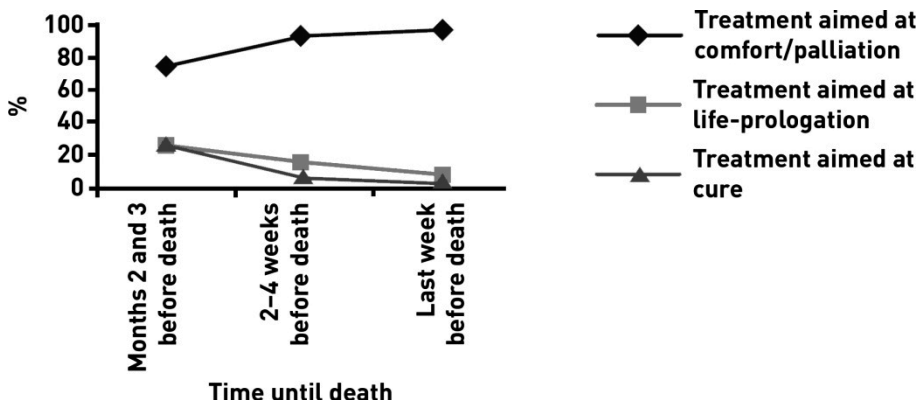
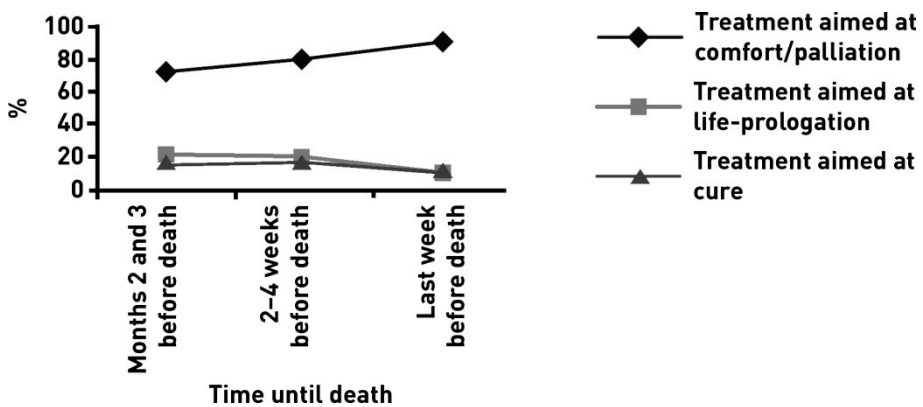


Figure 6.2 Important treatment aims for non-cancer patients.



In the last week of life, there was a significant difference between patients with cancer and other patients concerning treatment aimed at cure (cancer: $n = 4$, 3% versus non-cancer: $n = 13$, 13%, $P = 0.005$). Hence in the very last days of life, cure was more frequently an important treatment aim for patients with a non-cancer cause of death than for patients with cancer. Also in the 2–4 weeks before death, cure was more frequently an important treatment aim in patients with a non-cancer cause of death than in patients with cancer (cancer: $n = 8$, 6% versus non-cancer: $n = 16$, 17%, $P = 0.01$). However, there were no significant differences regarding treatments aimed at cure in months 2 and 3 before death.

In addition, there were no significant differences between the percentages of patients with cancer and other patients, regarding treatments aimed at life prolongation in the three time periods.

In the 2–4 weeks before death, palliation was an important treatment aim in significantly more cancer patients compared with non-cancer patients (cancer: $n = 128$, 93% versus non-cancer: $n = 77$, 82%, $P = 0.007$). In the last week and in months 2 and 3 before death, there were no significant differences regarding treatments aimed at palliation.

Coexistence of important treatment aims

Table 6.3 shows that treatments aimed at palliation coexisted with life-prolonging/curative treatment aims for 17% of the patients in months 2 and 3 before death. This coexistence was observed for 13% of patients in the 2–4 weeks before death, and for 8% in the last week before death.

Table 6.3 Coexistence of important treatment aims at three time periods, n (%)

Important treatment aims	Palliation plus cure and/or life prolongation are important aims (= coexistence)	No coexistence	Don't know/missing	Total
2 and 3 months before death	35 (17)	176 (83)	68	279
2-4 weeks before death	30 (13)	193 (87)	56	279
Last week before death	18 (8)	216 (92)	45	279

DISCUSSION

Summary

In the last week of life, palliation was an important treatment aim in almost all patients with a non-sudden cause of death. In the 2-4 weeks before death and months 2 and 3 before death, palliation was an important treatment aim in 89% and 73% respectively of patients with a non-sudden cause of death.

Cure and life prolongation were more often important in the time periods that were relatively far away from death. However, in the last week of life cure was still an important treatment aim for 7% of patients. These patients mainly had a respiratory or cardiovascular disease. In these patients, death may be more difficult to predict than in patients with cancer.

Whether life prolongation/cure was an important treatment aim at the same time as palliation was also investigated. It was expected that coexistence of important treatment aims would be common. This expectation was derived from Lynn and Adamson's model indicating that the palliative phase is a care continuum in which palliation interventions may be given simultaneously with curative or life-prolonging treatments. However, this expectation was not fully supported by the data: in months 2 and 3 before death, palliation and

cure and/or life prolongation were simultaneously important treatment aims for only 17% of patients. This finding shows that one treatment aim often prevails over another at any given time.

In addition, differences in treatment aims between cancer patients and other patients were tested. As expected, in the last month of life cure was an important treatment aim for significantly more patients with a non-cancer cause of death than for patients with cancer. In addition, it was found that palliation was an important treatment aim in a larger number of cancer patients compared with other non-suddenly deceased patients in the 2–4 weeks before death. Recognition of approaching death is probably more difficult in non-cancer patients than in cancer patients, and it may therefore also be more difficult for GPs to discuss the prognosis and end-of-life issues with non-cancer patients.

Strengths and limitations

So far, most palliative care research has focused on the terminal stages of life.¹⁵⁻¹⁹ In addition, palliative care research on the last months of life of a diverse group of patients is scarce.²⁰ This study, based on epidemiological data from a national representative network of general practices, is exceptional in this regard.

Another strength of the current study is the representativeness of the Sentinel Network for GPs in the Netherlands in terms of age and sex of the GP, and population density. Another strength is that the GPs participate in an existing sentinel network, which means that they were not just recruited for this palliative care study. This reduces the chance of bias in the findings.²¹

However, this study also has some limitations. Registrations of GPs were restricted to the last 3 months of life. Although this concerns a larger time span than in most other studies on palliative care, it would be interesting to explore whether treatments aimed at palliation may be also important in earlier phases before death.

Finally, a recall bias is possible due to the retrospective design. However, the authors expect that this bias will be small as the registration form was sent to the GP within 1 week of the patient's death.

Comparison with existing literature

Until a few years ago, researchers often used the terms ‘palliative’ and ‘terminal’ synonymously, and also made a fairly strict separation between the curative and palliative phases. In accordance with the model of Lynn and Adamson, the palliative phase is currently considered as a care continuum that starts with the diagnosis of a life-threatening illness.^{2,22} Van den Block et al found that a transition from cure to palliation often occurs late in the dying process and sometimes not at all.⁸ Starting late with palliative care may be due to late recognition of the approaching death, which may be a problem particularly in patients with chronic diseases other than cancer.

Fitzsimons et al pointed to the necessity of embracing the palliative care approach at an earlier stage, to address the needs of patients with life-threatening chronic illness.²⁰ Furthermore, Murray et al concluded that end-of-life care for patients with cardiac failure or other non-malignant diseases should be proactive and designed to meet specific needs.⁷ In addition, Pinnock et al pointed to the necessity of careful assessment of possible supportive and palliative care needs along people’s lifetime journey with COPD.⁶ However, the findings of the present study show that for almost all patients in the Netherlands (95%) where death is non-sudden, palliation was an important treatment aim in the last week of their life, although 7% still received treatment aimed at cure in this last week.

The finding that the vast majority of the subgroup of patients with a non-cancer cause of death received treatments aimed at palliation in the last phase of life indicates that, currently, Dutch GPs are also alert to the palliative care needs of non-cancer patients.

Implications for research and practice

Investigation of treatment aims in earlier phases of illness would be interesting. This corresponds with the idea in today’s palliative care policy and research that the palliative phase may already start with the diagnosis of a life-threatening disease. Future research could also consider whether supporting the patient had been an important treatment aim. The concept of ‘supportive care’ has gained in usage, for instance for people with chronic diseases and temporary decompensations or intercurrent illnesses. It would be interesting to explore whether supportive care is frequently given in the

very last period of life, and whether supportive care is often combined with treatments aimed at cure, life prolongation, or palliation.

In addition, it would be interesting to conduct a prospective longitudinal study, in which the GP perspective as well as the perspectives of relatives and patients on the treatments and the treatment aims could be explored. Furthermore, it would be relevant to focus on differences between patients with various types of cancer, as well as between various groups of patients with specific chronic diseases.

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GPs' identification of the diagnosis and of imminent death in patients who died non-suddenly: a national survey

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Submitted

ABSTRACT

Background

Nowadays, palliative care is considered as a care continuum that may start early in the course of the disease. In order to address the evolving needs of patients for palliative care in time, GPs should be aware in good time of the diagnosis and that death is imminent. The aim of the study was to gain insight into how long before a non-sudden death the diagnosis of the disease ultimately leading to death is made and on what kind of information the diagnosis is based. In addition, we aimed to explore when, and based on what kind of information, GPs identify imminent death.

Methods

A written questionnaire focusing on the GPs' experiences with their last patient who died non-suddenly was sent to a random representative sample of 850 GPs in the Netherlands.

Results

The data were analysed of the 297 GPs who responded. 76% of the reported cases were cancer patients and 24% were patients with another non-sudden cause of death. The diagnosis was made only in the last week of life for 15% of the non-cancer patients and 1% of the patients with cancer. GPs were most likely to have been informed of the diagnosis by the medical specialist, although particularly in the case of non-cancer patients GPs also relied on their own assessment of the diagnosis or on other information sources.

The GP remained unaware of the imminence of death until the last week before death in 26% of the non-cancer group, while this was the case for only 6% of the cancer patients. The recognition that death was imminent was most likely to be based on the GP's own observations of problems and/or symptoms.

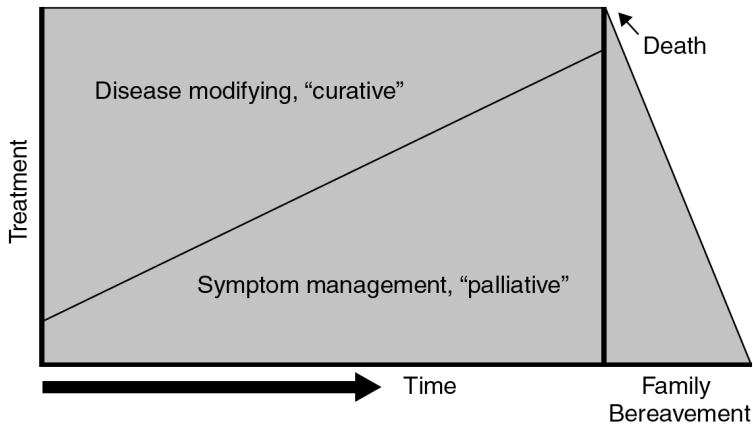
Conclusions

The GP often only becomes aware of the diagnosis and imminent death at a late stage in the disease trajectory, particularly in the case of non-cancer patients. It can be assumed in cases where the diagnosis and imminent death are only recognised at a late stage that palliative care is either started at a very late stage or not at all.

BACKGROUND

Nowadays, care providers, policymakers and researchers are increasingly aware that palliative care is broader than terminal care. Figure 7.1 shows the 'model' of Lynn and Adamson (2003), displaying palliative care as part of a care continuum that starts early in the trajectory of a chronic illness and that ends with the death of the patient and aftercare for relatives.¹

Figure 7.1. Palliative care as a care continuum (Lynn and Adamson 2003).



Timely diagnosis of a life-threatening disease as well as timely recognition of imminent death may be important in order to anticipate the frequent increase in symptoms and problems, to prevent crises, and to better meet patients' needs for palliative care. Because the GP is a key professional in palliative care^{2,3}, it is important that she/he is aware in good time of a diagnosis of a life-threatening condition and of imminent death.

To our knowledge, no previous studies have been conducted on what kind of information GPs use and in what phase of the illness trajectory GPs become aware of the diagnosis. Yet some studies have been conducted on identifying imminent death.^{4,5} Sullivan et al. performed secondary analyses of interviews with hospital physicians.⁵ They explored whether and when physicians reported that death was imminent. They found that 38% of physicians were uncertain when the patient was admitted whether the patient would die during this hospitalisation, but over the course of hospitalisation 86% reported that they knew that death was imminent. Eleven percent of physicians reported anticipating the patient would die weeks before the

death, 57.1% days before, and 18.3% hours before the death. Earlier recognition of imminent death was associated with greater reported overall satisfaction of the physicians with the end-of-life care provided to the patient. Furthermore, Abarshi et al. investigated how long before death GPs recognise that patients were likely to die in the near future.⁴ They reported that GPs never recognised that death was imminent in about a third of their patients with a non-sudden death.⁴ However, the study of Abarshi et al. did not explore which sources of information the GPs used to identify the imminence of death.

In addition, so far it has remained unclear whether there are differences between cancer patients and other patients with a non-sudden death cause regarding the 'when and how' of GPs' identification of the diagnosis and of impending death. However, common disease trajectories differ between patient groups⁶⁻⁸, which may also have consequences for GPs' awareness of the diagnosis and the identification of impending death. Lynn and Adamson and also Murray distinguished three common disease trajectories leading to a non-sudden death.^{1,9} First there is the common illness trajectory of patients with cancer, which is reasonably predictable and usually characterised by a clear terminal phase. In contrast, trajectories in patients with COPD or heart failure are often characterised by intermittent exacerbations and remissions and a relatively sudden death. In the frail elderly, such as people with dementia, there is often a prolonged gradual decline towards death. Since disease trajectories vary, it can be expected that the timing of the recognition of the diagnosis and of the imminence of death are also different.

We conducted this study among a random sample of GPs in the Netherlands in order to gain more insight into the 'how and when' of GPs' identification of the diagnosis and of the recognition of imminent death. The following research questions are addressed:

1. How long before death is the diagnosis of a disease ultimately leading to death made in cancer patients and in patients with another non-sudden cause of death?
2. On the basis of what kind of information sources do GPs become aware of the diagnosis of the disease leading to death?

3. How long before their patients die do GPs recognise that death is imminent in cancer patients and in patients with another non-sudden cause of death?
4. On the basis of what kind of information sources do GPs recognise that death is imminent?

METHODS

Design

A retrospective cross-sectional design was used based on survey data.

Study population and setting

A random sample of 850 Dutch GPs participated in this survey. The sample was drawn from a national registration base (NIVEL) with the addresses and background characteristics of all GPs working in the Netherlands.

Pilot and content of the questionnaire

The content of the questionnaire was largely based on existing questionnaires: in particular a questionnaire about end-of life care by GPs¹⁰⁻¹² and a registration form used by GPs participating in the Dutch Sentinel General Practice Network.¹³ GPs were asked to base their answers on the case of their last patient with a non-sudden death. We explained in the questionnaire that this could be a patient who died of cancer, heart failure, COPD, stroke, dementia, other chronic diseases or “gradual decline because of frailty and old age”.

Face validity, content validity and comprehensibility of the draft questionnaire were assessed by the steering committee, which included three scientists in the field of end-of-life care and two GPs. The usability and comprehensibility were tested further among ten other GPs. This resulted in some minor revisions, e.g. regarding the time period to which questions relate. The final version of the questionnaire consisted of 44 semi-structured questions. The questions that are used for the analysis in this paper (translated from Dutch to English) are presented in Box 7.1.

The random sample of 850 GPs received the final questionnaire, together with an explanatory letter and return envelope, in the summer of 2010. Reminders were sent after four weeks and seven weeks.

Box 7.1 Questions that are used for the analysis in this paper

1. What was the underlying disease leading to death? Only one answer possible.
 - Cancer, namely lung bowel breast prostate other, namely
 - Heart failure
 - Asthma/COPD
 - Stroke
 - Dementia
 - Slow decline because of old age
 - Other, namely
 - Unknown

2. How long before death was the diagnosis made of the disease that ultimately led to the patient's death?
 - ≤ 7 days before death
 - 1–4 weeks before death
 - 1–3 months before death
 - 4–6 months before death
 - 6–12 months before death
 - 1–2 years before death
 - More than 2 years before death
 - I don't know
 - Not applicable because

3. How did you become aware of the diagnosis? Multiple answers possible.
 - Information from the medical specialist(s)
 - Own diagnostics
 - Patient him/herself
 - Relative(s)
 - Other, namely
 - I don't know
 - Not applicable because

4. How long before death did you know that death was imminent for this patient?
- ≤ 7 days before death
 - 1–4 weeks before death
 - 1–3 months before death
 - 4–6 months before death
 - 6–12 months before death
 - 1–2 years before death
 - More than 2 years before death
 - I don't know
5. How did you know that death was imminent for this patient? Multiple answers possible
- Through problems and/or symptoms that the patient had and that I myself identified as the GP
 - Through information from the medical specialist(s)
 - Through information from home-care professionals
 - Through information from the patient's relative(s)
 - Other, namely
 - Not applicable because

Statistical analysis

All questionnaires were scrutinised for errors and missing data, and the data were digitised by scanning. A random sample of 15 questionnaires was checked for errors arising during scanning. No errors were found.

Descriptive analyses and Chi-square analyses were used to answer the research questions addressed in this paper. A Fisher exact test was used instead of a Chi-square test if the expected value for one or more of the cells was less than five.

Ethics

GPs received information about the aim and content of the research in an explanatory letter, which was sent together with the questionnaire. The anonymity of the GPs and their patients was strictly preserved throughout the data entry and analysis process.

According to Dutch law, no approval of a Medical Ethics Committee is needed for surveys among care professionals and for post-mortem anonymous patient data.

RESULTS

Response

Seventeen questionnaires were returned as 'undeliverable' (mainly because the address was unknown or incorrect), four other questionnaires were returned uncompleted because the GP was absent due to long-term illness or maternity leave and eleven were returned uncompleted because the GP had no experience with palliative care. Hence, 818 of the 850 GPs in the sample were considered eligible for this study. A total of 297 questionnaires were completed and returned (the net response rate was 36%, i.e. 297/818). About half of the respondents (47%) were aged between 40 and 54. The majority were male (57%) and 86% worked in a two-person or group practice (Table 7.1).

No differences between non-respondents and respondents were observed regarding gender, age, whether or not the GP had a solo practice, and degree of urbanisation (Table 7.1).

Table 7.1 Characteristics of sample of GPs in percentages

	Sample		P-value*
	Non-respondents (n=521)	Respondents (n= 297)	
Gender			0.717
Male	58.5	57.2	
Female	41.5	42.8	
Age			0.720
25-39	25.0	27.0	
40-54	46.8	47.2	
≥ 55	28.2	25.9	
Solo practice			0.169
Yes	17.9	14.1	
No	82.1	85.9	
Degree of urbanisation			0.787
Extremely urbanised / strongly urbanised	47.2	45.1	
Moderately urbanised	18.8	20.5	
Hardly urbanised / not urbanised	34.0	34.4	

*Chi-square analysis

Characteristics of the deceased patients dealt with in the GPs' questionnaires

Of the 297 patients described by the GPs as being their last patient with a non-sudden death, 153 were female (52%). The median age at death was 72 (range: 39–103). The majority (76%) died from cancer, while 24% had another non-sudden cause of death such as heart failure (33%), general decline because of old age (27%), asthma/COPD (9%), dementia (6%), amyotrophic lateral sclerosis (4%), renal failure (4%), stroke (1%), other (11%), and an unknown non-cancer cause of death (6%). 70% of the patients died at home, 13% in a care home and 10% of the patients died in a hospital.

Time between the diagnosis of the disease ultimately leading to death and the death

Table 7.2 Timing of the diagnosis of the disease ultimately leading to death and sources of information

Timing of diagnosis of disease ultimately leading to death	Cancer n=220** %	Non-cancer n=65** %	P-value*
In last six months before death (also including last month and last week)	41	49	0.234
In last month before death (also including last week)	6	29	<0.001
In last week before death	1	15	<0.001
GPs' information about diagnosis was based on: (more than one answer possible)	Cancer n=226 %	Non-cancer n=71 %	
Information from the medical specialist	73	61	0.046
GPs' own diagnostics	35	49	0.036
Information from the patient	15	7	0.082
Information from relatives	3	13	0.004
Other	4	1	0.692
Doesn't know	0	0	–
Not applicable	0	3	0.143

*Chi-square analyses: significant differences between group with cancer and non-cancer group are in bold

**12 missing values, including 'don't know/not applicable' answers

The diagnosis of the disease leading to the non-sudden death was made in the last six months of life (Table 7.2) in 41% of the group with cancer and 49% of the non-cancer group. The diagnosis was only made in the last month before death for 29% of the non-cancer patients versus 6% of the cancer patients ($p < 0.001$). The diagnosis was only made in the last week before death for 15% of the non-cancer patients versus only 1% of the cancer patients ($p < 0.001$).

In the case of 73% of the patients who died from cancer and 61% of the non-cancer patients ($p < 0.05$) GPs learnt about the diagnosis through information from the medical specialist – whether or not combined with other sources of information (Table 7.2). Particularly in the case of non-cancer patients, GPs also relied on their own diagnostics for the diagnosis (49%, significant differences between cancer and non-cancer patients, $p < 0.05$) or information from relatives (13%, significant differences between cancer patients and non-cancer patients, $p < 0.01$). In addition, GPs received information from the patients themselves about the diagnosis (Table 7.2).

Timing of GPs' recognition of imminent death and sources of information

In 86% of the group with cancer and 94% of the non-cancer group GPs' recognition of impending death was at some point in the last six months of life. GPs recognized that death was imminent in the last week before death in the case of 26% of the patients with a non-cancer death, versus 6% of cancer patients (Table 7.3, $p < 0.001$). GPs realised during the last month that death was imminent for 30% of the cancer patients versus 60% of the non-cancer patients ($P < 0.001$).

GPs' own observations of problems and/or symptoms was a source of information for the recognition of the imminent death of 78% of the patients who died of cancer versus 87% of the patients with another non-sudden cause of death. The medical specialist was a source of information for GPs' recognition of the imminent death of 53% of the cancer patients versus 28% of non-cancer patients (significant difference between cancer and non-cancer patients, $p < 0.001$). Particularly in the non-cancer group, GPs also frequently used information from home-care professionals and information

from relatives in the identification of imminent death (significant differences between cancer and non-cancer patients, see Table 7.3).

Table 7.3 Timing of GPs' recognition of imminent death and sources of information

Time between GPs recognition of imminent death and actual death	Cancer n=221** %	Non-cancer n=68** %	P-value*
In the last six months before death (including the last month and last week)	86	94	0.072
In the last month before death (including the last week)	30	60	<0.001
In the last week before death	6	26	<0.001
GPs' recognition of imminent death was based on: (more than one answer possible)	Cancer n= 225 %	Non-cancer n= 71 %	
GPs' observation of problems and/or symptoms	78	87	0.079
Information from medical specialist	53	28	<0.001
Information from home-care professionals	3	13	0.002
Information from relatives	15	27	0.020
Other	7	10	0.371
Not applicable	0	1	0.240

*Chi-squares analyses: statistically significant differences ($P<0.05$) between cancer and non-cancer group are in bold

**8 missing values, including 'don't know' answers

DISCUSSION

This study shows that the diagnosis was made for some patients only shortly before death. The diagnosis was not made until the last week of life in the case of 15% of the non-cancer group and 1% of the patients with cancer. Apparently, it is more difficult to make the diagnosis for patients with a non-cancer disease than for patients with cancer. The GPs' knowledge about the diagnosis was often based on multiple sources of information. For the majority of patients, GPs learnt about the diagnosis through information

from the medical specialist. GPs were more likely to rely also entirely or partly on their own diagnostics or information from relatives in the case of patients with diseases other than cancer.

In addition, our results show that GPs sometimes only became aware of the imminence of the non-sudden death late in the disease trajectory. The GP remained unaware that death was imminent until the last week before death in a quarter of the non-cancer group, while this was the case for only 6% of the cancer patients. This may be related to the fact that there is no clear diagnosis for some patients, such as the frail elderly with a general decline towards death. Another explanation may be that in the case of patients with COPD or chronic heart failure, for instance, the medical specialist has the main responsibility for the medical treatment of the patient until a late stage in the disease trajectory. If communication between the GP and medical specialists is poor, the patient's diagnosis may long be unknown to the GP, which hampers a timely start of palliative care provided by the GP.

The fact that GPs were asked to select their last patient with a non-sudden death may be related to the fact that GPs selected a relatively large number of cancer patients. Van der Velden reported in a death certificate study that about 77,000 people a year die from a chronic disease in the Netherlands. Just over half, 40,000 (52%), die from cancer.¹⁴ In our study, 76% of the patients with a non-sudden death selected by GPs had cancer and 24% were non-cancer patients. Apparently, GPs associate a non-sudden death more with cancer than with a non-cancer disease. The relatively low proportion in our study of patients with stroke (1%) or dementia (6%) is particularly striking. One possible explanation for this under-representation might be that patients with stroke or dementia are more likely to die in nursing homes with their own nursing-home physician being responsible for medical care.

Recommendations for practice

The present study shows that particularly in the case of non-cancer patients, GPs sometimes remain unaware of a life-threatening disease and of imminent death until late in the disease trajectory. This may have consequences for advance care planning and timely anticipation of the evolving symptoms and care needs. In line with Fitzsimons et al.¹⁵, we would like to point out the necessity of embracing the palliative care approach at an early stage of the disease in order to address the evolving needs of patients

with a life-threatening chronic illness in good time. Hence, a proactive attitude is required from GPs. From other recent research it is known that Dutch GPs in general have a reactive, rather than a proactive, attitude in the interactions with their patients.¹⁶ GPs consider it important for a patient to indicate what support he or she needs and they do not want to patronise the patient or give care that is not needed. However, at the end of life a more proactive approach, e.g. involving initiatives by the GP for advance care planning, may result in better matching of patients' and family members' existing and evolving care needs.

Strengths and limitations

A strength of this study is that data are included about both cancer patients and patients with other chronic diseases and the frail elderly. Previous studies of palliative care have mainly focused on cancer patients.¹⁷ However, the net response rate for the GP questionnaire was not high (36%), although comparable with other recent surveys among Dutch GPs.^{18,19} It is known that Dutch GPs have a high workload²⁰, which may explain why the non-response in this group is often high. It could be that GPs with a specific interest in palliative care were more likely to respond, which may have led to overestimation of the GP's role in making the diagnosis and the identification of imminent death.

Another limitation of this survey is that it only involved GPs. It would also be interesting to explore the perspectives of medical specialists on making the diagnosis and on the communication about the diagnosis with the GP, patient and family. In addition, nurses or close relatives, for instance, may play an important role in the recognition of impending death, and are also an important information source for the GP. Future multi-perspective research on making the diagnosis of life-threatening diseases and on the identification of impending death is therefore recommended.

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General Discussion

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.^{1,2}

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 2003³, and currently serves as inspiration for researchers, policymakers and professionals in the field of palliative care.⁴⁻⁶ 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.³

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”.⁷

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.⁸ 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.⁹ 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.¹⁰ 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.¹¹⁻¹⁶ Moreover, existing instruments often focus on very specific target groups, for example relatives of patients in the final stage of dementia¹⁶, persons involved in palliative cancer care¹⁷ or persons in a hospice setting.¹⁸ 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).¹⁹ 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.²⁰ 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 developed²¹, 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.²² 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.²³ 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 predict²⁴⁻²⁶, 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.³

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.²⁷⁻²⁹), 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.^{30,31} 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.³²

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'³³ was performed by asking for feedback on the analysis from one of the interviewed GPs. Moreover, 'peer debriefing'³³ 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.^{22, 34-38} 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.³⁹ 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.⁴⁰⁻⁴¹ It is known that Dutch GPs have a heavy workload⁴², 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.⁴³ 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^{44–45} 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.⁴⁶ 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 indicators¹ 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, 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 patients⁴⁷, 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.⁴⁸

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, 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'.⁴⁹ 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).⁵⁰ 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.⁸ 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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Summary

In the Netherlands, the government has been actively promoting the development of palliative care since the mid 1990s. Two important policy priorities are (a) more transparency in the quality of palliative care and (b) the promotion of palliative care early in the disease trajectory. These priorities prompted the research presented in this thesis.

The development of palliative care in the Netherlands and the government's incentive policy are described in the General Introduction (**Chapter 1**). This chapter also gives an overview of the two parts of the thesis. The first part (Chapters 2, 3 and 4) addresses research on quality indicators. In this thesis, 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". Quality indicators are important in current healthcare as a means of generating transparent quality information.

The second part (Chapters 5, 6 and 7) concerns research regarding the model of Lynn and Adamson (2003), which describes palliative care as a care continuum that starts early in the course of the disease. According to this model, curative and life-prolonging treatments may be given alongside palliative treatments, with a gradual shift to an emphasis on palliation.

Chapter 2 details the development of a set of quality indicators that covers all the domains of palliative care: physical, psychosocial and spiritual aspects as well as aftercare for relatives. The development trajectory consisted of several phases. First, an inventory was made of existing relevant quality indicators. In the second phase, interviews with patients, relatives and caregivers and consultation of experts provided input for the development of the draft set of quality indicators. In the third phase, a draft set was tested for feasibility and usability. This development trajectory resulted in a set of 43 indicators for palliative care. The instrument used to measure many of these quality indicators is the Consumer Quality Index (CQ-index) Palliative Care, described in the third and fourth chapters.

Chapter 3 presents the development of the patient version of the CQ-index Palliative Care. A CQ-index is a structured questionnaire for measuring quality indicators from the care users' perspective. A CQ-index asks for care users' actual care experiences, unlike many traditional quality instruments, which ask directly about care users' satisfaction with care. Priorities for

quality improvement can be identified by relating answers about actual care experiences to answers about the importance of different aspects of care. The development of the CQ-index Palliative Care consisted of several stages. The first phase (construction phase) consisted of a literature study, focus groups and individual interviews with relatives, patients and caregivers. Subsequently, a draft questionnaire was developed and tested among a small group of patients, the steering committee and other experts. In the second phase, data were collected among a larger group of patients and used to perform psychometric analyses. The respondents were patients with a maximum life expectancy of six months or less and/or who were receiving palliative treatment. The main aims of this psychometric testing phase were to shorten the questionnaire and to assess its psychometric properties. In addition, this phase also gave an indication of the priorities for quality improvement. The three care aspects with the highest priorities for improvement were 'support when the patient feels depressed', 'support when the patient is anxious' and 'support when the patient has shortness of breath'.

Chapter 4 focuses on the development of the relatives' version of the CQ-index Palliative Care. The relatives' questionnaire was administered to close relatives/contact persons of patients who died non-suddenly six weeks to six months earlier. Psychometric analyses resulted in six scales. Aftercare was the care aspect with the highest priority for quality improvement. Like the patients' version of the CQ-index Palliative Care, the version for relatives turns out to be well-suited to setting priorities for quality improvement within a care organisation.

If future research shows that this CQ-index (relatives' version as well as patient version) also has discriminative power, the instrument can also be used for comparing the quality of different care organisations.

Chapter 5 describes a qualitative interview study among GPs. The GPs were asked how they identify a need for palliative care in patients with cancer or other chronic diseases and in the frail elderly. GPs identify a need for palliative care based on a combination of signals that are often subtle. Some examples of the signals from patients are increasing care dependency and not recovering after intercurrent diseases or infections. In addition, signals from family members or reports from medical specialists can lead a GP to

identify a need for palliative care in a patient. GPs often only gradually become aware of palliative care needs, relatively late in the disease trajectory, particularly when their patients have diseases other than cancer – for example, patients with COPD or the frail elderly. This contrasts with the model of Lynn and Adamson, which assumes that palliative care starts early in the disease trajectory.

Chapter 6 describes a study of treatment aims in the last three months of life of patients who died non-suddenly. In this study, registration forms were used from a representative Sentinel Network of GPs in the Netherlands. In month two and three before death, palliation was an important treatment aim in 73% of the patients, increasing to 95% in the last week of life. Treatment was aimed at life prolongation for 25% of the patients in month two and three before death, decreasing to 9% in the last week of life. Furthermore, 22% of the patients were (also) receiving treatments aimed at cure in month two and three before death, decreasing to 7% of patients in the last week of life. The patients who were still receiving treatment aimed at cure in the last week of life mainly had a cardiovascular or respiratory disease.

We also found that palliation and cure/life prolongation were simultaneously important treatment aims for only a minority of patients (17% in month two and three before death). This is less than might be expected on the base of the model of Lynn and Adamson, which assumes that curative treatments may be given alongside palliative treatments.

In **Chapter 7** a survey study is presented on when the diagnosis of the disease that ultimately led to death was made and the recognition of impending death by GPs. In this written questionnaire, GPs were asked about the last patient they had had who died non-suddenly. GPs sometimes only became aware of the diagnosis at a late stage in the case of patients with a disease other than cancer (for example, heart failure or general decline because of frailty). For 15% of the patients with a disease other than cancer the diagnosis was only made in the last week of life according to the GP. Information on the diagnosis usually came from the medical specialist. However, in the case of non-cancer patients in particular the GP also relied on other sources of information, such as his/her own diagnostics.

In addition, an imminent death was sometimes only recognised at a late

stage, especially in the case of patients who died from a disease other than cancer. The GP became aware that death was imminent only in the last week before death for 26 % of the patients with a disease other than cancer, compared to 6% of the cancer patients. GPs generally recognised that death was imminent by observation of the patient's problems and/or symptoms. If the diagnosis is being made at a late stage and imminent death is only recognised late, it can be assumed that palliative care is being started very late or not at all.

Chapter 8, the General Discussion, provides the main findings, reflections and conclusions. The first part of this final chapter looks back on the sub-studies dealing with the quality indicators. The decision to develop mainly outcome indicators, rather than structure or process indicators, is explained. In addition, the decision to develop and use a CQ-index Palliative Care rather than a traditional satisfaction questionnaire is justified.

The second part considers the sub-studies relating to the model of Lynn and Adamson. There is a discussion about the extent to which GPs' perspectives and experiences are in accordance with the idea that palliative care is a care continuum that starts early in the disease trajectory. The chapter ends with recommendations for care providers, policymakers and researchers.

Samenvatting

***Nieuwe ontwikkelingen in de palliatieve zorg:
kwaliteitsindicatoren en het palliatieve
zorgcontinuüm***

Vanaf halverwege de jaren '90 is palliatieve zorg door de Nederlandse overheid gestimuleerd. Belangrijke prioriteiten in het overheidsbeleid zijn:

- (a) meer transparantie van de kwaliteit van de palliatieve zorg en
- (b) stimulering van palliatieve zorg vroeg in het ziekte-traject.

Deze prioriteiten waren aanleiding voor het onderzoek gepresenteerd in dit proefschrift.

In de Algemene Inleiding (**Hoofdstuk 1**) wordt de ontwikkeling van palliatieve zorg in Nederland en het stimuleringsbeleid van de overheid beschreven. Dit hoofdstuk geeft ook een overzicht van de twee delen van het proefschrift. Het eerste deel (hoofdstukken 2, 3 en 4) gaat over onderzoek naar kwaliteitsindicatoren. In dit proefschrift worden kwaliteitsindicatoren gedefinieerd als “meetbare aspecten die een indicatie geven over de kwaliteit van de zorg en die betrekking hebben op structuren, processen of uitkomsten van zorg”. Kwaliteitsindicatoren worden in de gezondheidszorg ingezet voor het genereren van transparante kwaliteitsinformatie.

Het tweede deel (hoofdstukken 5, 6 en 7) gaat over onderzoek dat aansluit bij het model van Lynn en Adamson (2003), waarin palliatieve zorg wordt weergegeven als een zorgcontinuüm dat begint in de vroege fase van de ziekte. Volgens dit model kunnen curatieve en levensverlengende behandelingen tegelijkertijd met palliatieve behandelingen gegeven worden, waarbij geleidelijk de nadruk op palliatie komt te liggen.

In **Hoofdstuk 2** wordt de ontwikkeling van een set kwaliteitsindicatoren beschreven die alle domeinen van palliatieve zorg omvat: lichamelijke, psychosociale en spirituele aspecten en nazorg voor nabestaanden. Het ontwikkelingstraject bestond uit verschillende fasen. Eerst werd een inventarisatie uitgevoerd naar bestaande relevante kwaliteitsindicatoren. In de tweede fase zijn interviews met patiënten, naasten en zorgverleners gehouden en zijn experts geraadpleegd. In de derde fase werd de haalbaarheid en bruikbaarheid van een conceptset getest. Dit ontwikkeltraject resulteerde in een set van 43 kwaliteitsindicatoren voor palliatieve zorg. Een groot deel van deze kwaliteitsindicatoren moet gemeten worden met de Consumer Quality Index (CQ-index) Palliatieve Zorg, beschreven in het derde en vierde hoofdstuk.

Hoofdstuk 3 beschrijft de ontwikkeling van de patiëntenversie van de CQ-index Palliatieve Zorg. Een CQ-index is een gestructureerde vragenlijst voor het meten van kwaliteitsindicatoren vanuit gebruikersperspectief. Een CQ-index vraagt naar de feitelijke ervaringen van zorggebruikers in tegenstelling tot veel traditionele kwaliteitsinstrumenten die rechtstreeks naar de tevredenheid met de zorg vragen. Prioriteiten voor kwaliteitsverbeteringen worden vastgesteld door antwoorden over feitelijke zorgervaringen te combineren met antwoorden op vragen over het belang van bepaalde zorgaspecten. De ontwikkeling van de CQ-index Palliatieve Zorg bestond uit verschillende fasen. De eerste fase (constructiefase) bestond uit een literatuurstudie, focusgroepen en individuele interviews met naasten, patiënten en zorgverleners. De conceptvragenlijst werd vervolgens ontwikkeld en getest onder een kleine groep patiënten, de begeleidingsgroep en andere experts. In de tweede fase werden psychometrische analyses uitgevoerd op basis van data verzameld onder een grotere groep patiënten. Deze respondenten hadden een maximale levensverwachting van zes maanden of minder en/of ontvingen een palliatieve behandeling. Hoofddoel van deze psychometrische testfase was het instrument inkorten en de psychometrische eigenschappen beoordelen. Daarnaast gaf deze fase ook een indicatie van prioriteiten van kwaliteitsverbetering. De drie zorgaspecten met de hoogste prioriteit voor verbetering waren 'begeleiding wanneer de patiënt zich somber voelt', 'begeleiding wanneer de patiënt angstig is' en 'begeleiding wanneer de patiënt benauwd is'.

Hoofdstuk 4 gaat over de ontwikkeling van de nabestaandenversie van de CQ-index Palliatieve Zorg. De nabestaandenversie werd voorgelegd aan naasten/contactpersonen van patiënten die zes weken tot zes maanden geleden niet-plotseling waren overleden. Psychometrische analyses resulteerden in zes schalen. Nazorg was het aspect met de hoogste prioriteit voor kwaliteitsverbetering. Evenals de patiëntenversie van de CQ-index Palliatieve Zorg blijkt de nabestaandenversie geschikt te zijn om prioriteiten voor kwaliteitsverbetering binnen een zorgorganisatie vast te stellen. Als uit toekomstig onderzoek blijkt dat deze CQ-index ook discriminerend vermogen heeft, dan kan het instrument ook gebruikt worden voor vergelijkingen van kwaliteitsscores van verschillende zorgorganisaties.

In **Hoofdstuk 5** wordt een kwalitatieve interviewstudie onder huisartsen beschreven. Aan huisartsen werd gevraagd hoe zij een behoefte aan palliatieve zorg herkennen bij patiënten met kanker of andere chronische ziektes en bij kwetsbare ouderen. Een combinatie van – veelal subtiele – signalen leidt ertoe dat huisartsen een behoefte aan palliatieve zorg herkennen. Signalen van patiënten zijn bijvoorbeeld toenemende zorgafhankelijkheid en niet herstellen na bijkomende ziektes of infecties. Ook signalen afkomstig van familieleden of informatie van de medisch specialist kunnen maken dat een huisarts bij een patiënt een behoefte aan palliatieve zorg identificeert. Vooral bij patiënten met een andere ziekte dan kanker – bijvoorbeeld patiënten met COPD of kwetsbare ouderen – wordt de huisarts zich vaak geleidelijk en relatief laat in het ziekteproces bewust van een behoefte aan palliatieve zorg. Dit contrasteert met het model van Lynn en Adamson dat er van uitgaat dat palliatieve zorg vroeg in het ziekteproces start.

Hoofdstuk 6 beschrijft een studie over behandeldoelen in de laatste drie maanden van het leven van patiënten die niet-plotseling zijn overleden. In deze studie zijn registratieformulieren van een representatief huisartsennetwerk ('peilstations') in Nederland gebruikt. In maand twee en drie voor het overlijden was palliatie een belangrijk behandelgoal bij 73% van de patiënten oplopend tot 95% in de laatste week van het leven. Behandeling gericht op levensverlenging kwam bij 25% van de patiënten voor in maand twee en drie voor het overlijden, afnemend tot 9% in de laatste week van het leven. In maand twee en drie voor het overlijden ontving 22% van de patiënten (ook) nog behandelingen gericht op genezing, afnemend tot 7% van de patiënten in de laatste week van het leven. Deze patiënten die in de laatste week van het leven nog curatieve zorg ontvingen hadden hoofdzakelijk een cardiovasculaire of respiratoire ziekte.

Ook vonden we dat bij een minderheid van de patiënten (17 % in maand twee en drie voor het overlijden) behandelingen gericht op palliatie tegelijkertijd werden gegeven met behandelingen gericht op genezing/levensverlenging. Dit contrasteert met het model van Lynn en Adamson waarin curatieve en palliatieve behandelingen tegelijkertijd gegeven worden.

In **hoofdstuk 7** wordt een vragenlijstonderzoek gepresenteerd over het vaststellen van de diagnose van een aandoening die uiteindelijk tot het overlijden zal lijden en van een naderend overlijden door huisartsen. In de schriftelijke vragenlijst werden huisartsen bevraagd over hun laatste patiënt die niet-plotseling overleden was. Bij patiënten met een andere ziekte dan kanker (bijvoorbeeld hartfalen of algehele achteruitgang als gevolg van ouderdom) kwam de huisarts soms in een laat stadium op de hoogte van de diagnose: bij 15% van de patiënten met een andere ziekte dan kanker was de diagnose volgens de huisarts pas gesteld in de laatste week van het leven. Meestal was informatie over de diagnose afkomstig van de medisch specialist. Echter, vooral bij niet-kanker patiënten baseerde de huisarts zich ook vaak op andere informatiebronnen, zoals zijn/haar eigen diagnostiek.

Ook een naderend overlijden werd soms laat herkend, vooral bij de patiënten die aan een andere ziekte waren overleden dan kanker. Bij 26% van de patiënten met een andere ziekte dan kanker tegenover 6% van de kankerpatiënten, zag de huisarts de naderende dood pas in de laatste week voor het overlijden aankomen. Een naderend overlijden werd door de huisarts meestal herkend door observaties van problemen en symptomen van de patiënt.

Als de diagnose laat gesteld wordt en een nabije dood laat herkend wordt, dan kan verondersteld worden dat palliatieve zorg erg laat of helemaal niet gestart wordt.

Hoofdstuk 8, de Algemene Discussie, geeft de belangrijkste bevindingen, reflecties en conclusies weer. In het eerste deel van dit afsluitende hoofdstuk wordt teruggekeken op de deelstudies die gaan over kwaliteitsindicatoren. Onder meer wordt de keuze om hoofdzakelijk uitkomstindicatoren in plaats van structuur- of procesindicatoren te ontwikkelen uitgelegd. Tevens wordt de keuze om een CQ-index Palliatieve Zorg in plaats van een traditionele tevredenheidsvragenlijst te ontwikkelen en te gebruiken verantwoord.

In het tweede deel wordt teruggeblikt op de deelstudies die aansluiten bij het model van Lynn en Adamson. Onder meer wordt ingegaan op de vraag in welke mate de perspectieven en ervaringen van huisartsen in overeenstemming zijn met het idee dat palliatieve zorg een zorgcontinuüm is dat al vroeg start in het ziekte-traject. Het hoofdstuk eindigt met aanbevelingen voor zorgverleners, beleidsmakers en onderzoekers.

Dankwoord

Met het schrijven van dit dankwoord is er een einde gekomen aan het grote avontuur dat in mei 2008 begon als een project van tien maanden, maar uitgroeide tot dit proefschrift. Nu ik de laatste hand leg aan dit werk, is dit een goed moment voor reflectie.

“Omnia mutantur, nihil interit” is een citaat uit het prachtige werk “Metamorphoses” van de legendarische Romeinse dichter Ovidius. Letterlijk vertaald:

“Alles verandert, niets vergaat” en vrij vertaald naar het onderwerp van dit proefschrift:

“De palliatieve zorg is volwassen geworden, maar niets van het oorspronkelijke is weggelaten”.

Ik heb het schrijven van dit proefschrift ervaren als één groot avontuur. Ik denk dat het schrijven van een proefschrift goed te vergelijken is met het beoefenen van bergsport. Een goede bergsporter weet dat een tocht door de bergen begint met een gedegen voorbereiding. Conditie opbouwen. Vaardigheden leren, zoals kaart en kompas leren lezen om je weg te vinden door de bergen. Goede materialen om je tocht te volbrengen zoals een comfortabel jack waarin je kunt wegduiken bij slecht weer. Betrouwbare reisgenoten, waar je op kunt rekenen als het even tegen zit. Deze ingrediënten zijn ook bij het schrijven van dit proefschrift onontbeerlijk gebleken. Tijdens deze reis ben ik veel mensen tegengekomen die ik graag wil bedanken voor hun ondersteuning.

Vanaf dag één stond het onderzoek als een huis. Anneke: vanaf mei 2008 werk ik intensief met je samen. Je bent een groot inspirator vanaf het begin van deze tocht. Je hebt me geleerd om teksten scherper te formuleren, tot het uiterste te gaan, maar het daarna ook los te laten. Belangrijke vaardigheden als onderzoeker én als bergsporter.

Ons avontuur begon in mei 2008 met het ontwikkelen van een vragenlijst om de kwaliteit van palliatieve zorg te meten vanuit patiënten- en naastenperspectief. Dit groeide uit tot een volwaardig promotietraject toen we in 2009 het project ‘Vroege herkenning van de palliatieve fase’ opstartten. Ik heb genoten van deze bijzondere tijd. Dank je wel voor je deskundige begeleiding, scherpe blik, sterke combinatie van wetenschappelijke en pragmatische aanwijzingen, supersnelle reacties op mijn hersenspinsels en manuscripten, maar bovenal het vertrouwen dat je van meet af aan in me hebt gehad!

Luc: jij bent als 2^e promotor zeer nauw betrokken geweest bij mijn reis, met alle pieken en dalen. Je betrokkenheid bij dit proefschrift heb ik zeer gewaardeerd. Ik heb veel geleerd van je kritische vragen op manuscripten en je methodologische aanwijzingen. Daarnaast heb ik je leren kennen als

iemand die bergen werk verzet op internationaal gebied: je bijdrage aan het internationale werkveld van de palliatieve zorg is ongekend! Het is voor mij erg inspirerend geweest om daar onderdeel van uit te mogen maken. Dank dat je mijn 2^e promotor wilt zijn!

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Op mijn tocht de afgelopen jaren heb ik de luxe gehad om met twee verschillende gezelschappen te mogen reizen. Ik ben begonnen op het NIVEL in 2008 waar ik de basis van mijn proefschrift heb kunnen leggen. NIVEL heb ik leren kennen als een zeer inspirerende werkomgeving: een prachtige combinatie van wetenschappelijk, maar praktijkgericht onderzoek.

De basis van mijn proefschrift die ik bij het NIVEL heb gelegd, heb ik verder uitgebouwd bij het EMGO+ instituut van het VUmc. Het EMGO+ instituut bestaat uit mensen met zeer uiteenlopende expertises. Ik heb het EMGO+ instituut ook ervaren als een erg prettige werkomgeving.

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Niet te vergeten: patiënten en nabestaanden van patiënten die een onvergetelijke bijdrage hebben geleverd aan de totstandkoming van dit proefschrift. Ik ben geraakt door jullie openheid! Groot is ook mijn dank aan zorgverleners die deel hebben genomen aan de metingen van de kwaliteitsindicatoren en CQ-index Palliatieve Zorg. Ik waardeer jullie betrokkenheid. Maar ook huisartsen hebben een onschatbare bijdrage geleverd aan dit proefschrift: dank voor het invullen van mijn vragenlijst en ook jullie bereidwilligheid en openheid om deel te nemen aan de interviews.

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Het einde van dit proefschrift en deze tocht is nu dan echt in zicht, ik sluit af met een laatste citaat van Ovidius: "Factum abiit: monumenta manent", letterlijk vertaald: "De daad is verleden, het teken ervan blijft." Dit proefschrift....

About the author

Susanne Jaquelin Johannes Claessen was born on October 2, 1979 in Heerlen, the Netherlands. After graduating in 1998 from pre-university education (Gymnasium) in Sittard, Susanne started studying Medicine at the Maastricht University and graduated in 2004. Subsequently, she started working as a medical doctor. In 2007, Susanne started working as a researcher on a project at the department of Rheumatology of the Erasmus Medical Center about treatment on base of a prediction model of patients in the Rotterdam Early Arthritis Cohort. In 2008, she started working at the Netherlands Institute for Health Services Research (NIVEL). She was involved in the development of quality indicators for palliative care in the Netherlands and she has developed the Consumer Quality Index (CQ-index) Palliative Care. This is a structured questionnaire for measuring care users experiences and consists of a patient and relative version. The research regarding quality indicators and the CQ-index Palliative Care resulted in the first part of this thesis. In September 2009, Susanne started working on the second part of her thesis at the Department of Public and Occupational Health of the EMGO Institute for Health and Care Research of the VU University Medical Center. The research which resulted in the second part of this thesis involved a study on the palliative care continuum from the GPs' perspective. During her PhD she officially became epidemiologist (A). After obtaining her PhD Susanne will work as a general practitioner trainee.

Susanne Claessen is married with Jeroen de Leeuw.

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