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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}

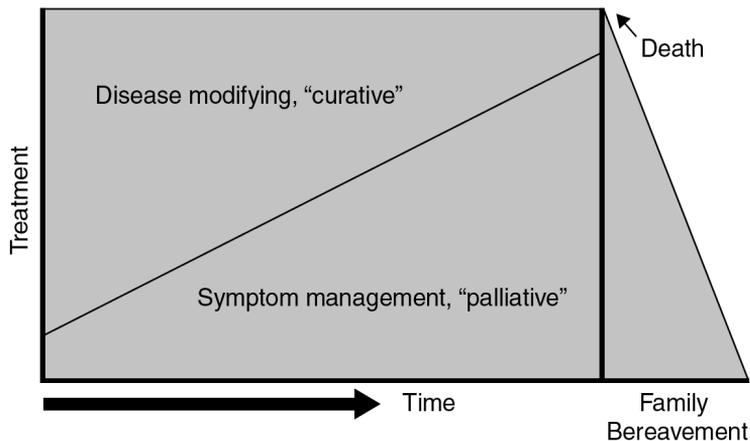
Quality indicators can be relatively 'objective' in nature, such as quality indicators for the prevalence of symptoms in patients receiving palliative care. In addition, subjective quality indicators can be used reflecting care providers' or care users' appraisal of the quality of care. In the Netherlands, 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.

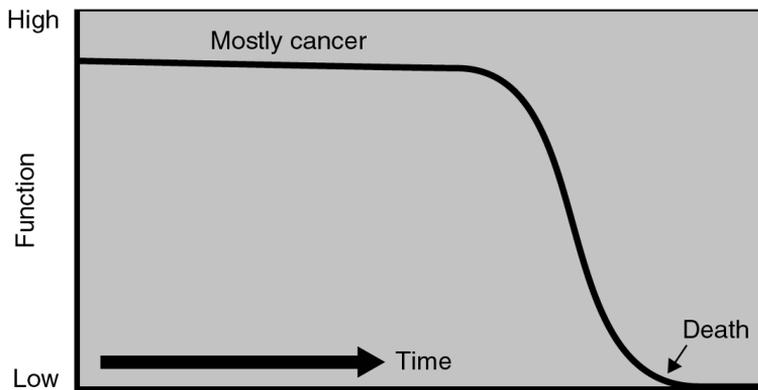
So far, there is little empirical data available on the timing of the transition from curative or life-prolonging treatments to palliative treatments and the possible coexistence of various treatment aims. One of the issues addressed in the second part of the thesis is what are the important treatment 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

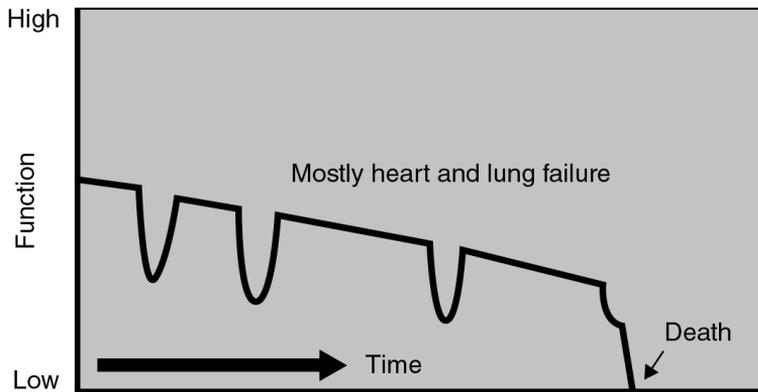
substantial period of comfort and high functioning. In contrast, the common disease trajectory of patients with heart failure or COPD is characterised by long-term limitations, intermittent exacerbations and remissions, resulting in a relatively sudden death. Finally, in the frail elderly, such as people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

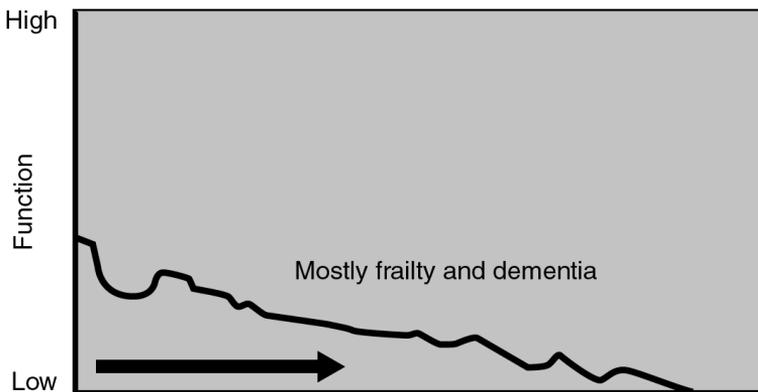
Figure 1.2 Disease trajectories at the end of life.



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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