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Claessen, S.J.J.

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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.