Opportunities to improve palliative care: towards a more patient-centred and proactive approach

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CHAPTER 1

General introduction

1. PALLIATIVE CARE AND ITS RATIONALE

Palliative care aims to '*improve the quality of life of patients and their families, who are facing a life-threatening condition or frailty, through prevention and relief of suffering by means of early identification and careful assessment, and treatment of problems of a physical, psychological, social and spiritual nature. Over the course of the illness or frailty, palliative care aims to preserve autonomy, access to information and the opportunity to make choices*.' This definition was published by the Netherlands comprehensive cancer organisation (IKNL) in 2017 and is based on the World Health Organisation (WHO) definition from 2002.[1, 2] Ideally, palliative care is integrated into standard care timely during the illness trajectory, and is deemed appropriate to prepare patients and their family for the end of life, in the near or far future.[1, 2] Palliative care is often referred to as an *approach*, rather than a medical specialism.[1, 3] The Dutch Quality Frame work on Palliative care characterises palliative care as follows:

- palliative care can be provided **concurrently** with disease-modifying treatment;
- generalist healthcare professionals and, when required, specialist healthcare professionals and volunteers, work **together** as an interdisciplinary team with patients and their family to tailor treatment to the needs, wishes and values of the patient;
- to ensure continuity, care is **coordinated** by one central healthcare professional;
- the wishes of patients and their family about dignity are **acknowledged** and **supported** throughout the disease trajectory and the process of dying and after death.[2]

IKNL underlined the need of palliative care in their nation-wide report published in 2014: the most common causes of death in the Netherlands are non-sudden conditions, which are indications for initiating palliative care.[4] In 2017, 105.766 patients in the Netherlands died of non-sudden causes. It is estimated that the proportion of non-sudden deaths is around 70% of all deaths (sudden and non-sudden deaths). People who died non-suddenly most frequently died because of cancer (44%), organ failure (25%) or dementia (11%).[5]

The number of non-sudden deaths will further increase due to ageing, improved life expectancy in general and increase in numbers of patients with chronic conditions.[4] The population that is 80 years or older accounts for 4.5% of the total Dutch population. In the Netherlands, life expectancy increased from 72 years for men and 79 years for women in 1980, to 80 and 83 years respectively in 2018.[6] In 2019, the Lancet Commission on Palliative Care and Pain Relief published a paper stating that in 2060, 47% of all people will die after a period of serious health-related suffering. In 2060, the increase in serious health-related suffering will be mostly due to cancer and dementia.[7]

1.1 Early integration of palliative care

Accumulating evidence shows that a palliative care approach can improve the quality of life of patients and their families. In 2016, Kavalieratos et al. published a systematic review and meta-analysis including 43 randomised controlled trials on the association between palliative care and outcomes of patients and their family. They demonstrated that palliative care improves patients' quality of life, which was clinically significant after one and three months of follow up. Other effects of palliative care include reduced symptom burden, more occurrence of advance care planning, improved patient and care giver satisfaction, and less use of healthcare resources.[8]

Several randomised controlled trials have shown the benefits of early integration of palliative care into standard care. A Cochrane review from 2017 on the effect of early palliative care provided by specialised palliative care teams for adults with advanced cancer demonstrated that early palliative care improved health-related quality of life and reduced symptom intensity.[9] A more recent Belgian randomised controlled trial showed that systemic integration of palliative care into oncologic care versus standard oncologic care improved quality of life after twelve weeks in patients with cancer with a life expectancy of twelve months.[10] Patients who received early palliative care reported a better quality of life six months and one month before they died, compared to patients who received standard care.[11]

1.2 The quality of end-of-life care

Early integrated palliative care should be available for each patient because it can prevent sub-optimal and inappropriate care. De Schreye et al. defined inappropriate care as '*treatment and/or medication in which the expected health benefit (e.g., increased life expectancy, improved functional capacity) does not exceed the expected negative consequences (e.g., morbidity, anxiety, pain) by a sufficiently wide margin that the procedure is worth doing, exclusive of cost*.'[12]

Earle et al. formulated quality indicators for studying end-of-life care in cancer patients.[13] Their four major categories of poor-quality end-of-life care are:

- initiation of a new anti-tumour regimen or continuing current treatment until near death;
- recurrent visits to the emergency department, hospitalisations, admissions to the intensive care unit near death;
- no or late enrolment in hospice care;
- death in an acute hospital setting.

The use of healthcare resources increases in the last phase of life. A study on healthcare utilisation in the last month of life by all Dutch patients who died of or with cancer in 2017, showed that palliative care provided by clinicians not specialised in palliative care was registered in 39% in the last year before death. This study further demonstrated that 34% of patients received potentially inappropriate end-of-life care in the last month of life according to Earle's quality indicators: 5% received chemotherapy, 6% were admitted to the intensive care unit, 8% spent more than fourteen days in-hospital, 9% were hospitalised twice or more often, 12% had visited the emergency department more than once and 20% died in-hospital. Potentially inappropriate end-of-life care occurred five times less in patients who received palliative care at least thirty days before death.[14, 15] A study on medication use in the last days of life in the Netherlands reported that 27% of the patients still were prescribed preventative medication on the day they died.[16] Another Dutch study found that clinicians order less diagnostic procedures and prescribe less preventive medication in the last 72 and 24 hours before the patient dies if they are aware of the patient's impending death.[17]

Randomised controlled trials conclude that integration of specialist palliative care can prevent inappropriate care at the end of life. Temel's landmark study from 2010, in which 151 patients with metastatic non-small-cell lung cancer were randomised to palliative care plus standard oncological care or standard care alone, showed that in patients receiving palliative care, end-of-life care was less aggressive according to Earle's quality indicators.[18, 19] Maltoni et al.'s randomised controlled trial reported that 107 patients with advanced pancreatic cancer who received palliative care (versus standard oncologic care, n=100) were admitted to a hospice more often, were in hospice care for a longer period and underwent chemotherapy less often in the last thirty days of life.[20]

2. PALLIATIVE CARE IN THE NETHERLANDS

2.1 The generalist plus specialist palliative care model

In the Netherlands, 32% of the patients die at home and 25% die in the hospital.[5, 21] Many healthcare professionals provide care to patients who are in the last phase of life and their family. It is warranted that all healthcare professionals working with vulnerable patients are aware of the benefits of palliative care integrated into standard care for quality of life and prevention of inappropriate end-of-life care. Also, they should know their own role in providing such care. To improve palliative care provision among all healthcare professionals, palliative care in the Netherlands is organised in line with Quill and Abernethy's concept of generalist (or: primary) palliative care plus specialist palliative care.[22]

Healthcare professionals providing generalist palliative care are those who have basic knowledge and skills in providing palliative care. This includes basic management of pain and other symptoms; basic management of depression and anxiety; and basic ability to have conversations about prognosis, goals of treatment, suffering and code status. Specialist palliative care is the responsibility of clinicians specialised in palliative care. They manage refractory pain or other symptoms; manage more complex depression, anxiety, grief, and existential distress; assist with conflict resolution regarding goals or methods of treatment; and assist with addressing cases of near futility. Both generalist and specialist palliative care are provided with a multi-dimensional perspective. Responsibilities of generalist and specialist palliative clinicians are described by Henderson et al.[23] From January 2017, every hospital in the Netherlands proving oncological care has a palliative care consultation team.[24] Specialist palliative care consultation teams support patients, family and primary care teams. They also have nonclinical responsibilities, such as teaching generalist palliative care clinicians, reporting delivered care and conducting or participating in palliative care research.[4, 23]

From 2014 to 2020, the Dutch government funded the National Palliative Care Programme called *Palliantie, meer dan zorg*.[25] This programme aimed to raise awareness and guarantee good palliative care for every citizen in the right place and at the right moment and provided by the right healthcare professionals. Themes of the *Palliantie* programme were awareness and culture; organisation; continuity of care; care-related interventions; and patient participation.[26] These themes are worked on within three main pillars: research; education; and implementation. *Palliantie* has made it possible to further develop tools to improve identification of palliative care needs, care for family, advance care planning and a care protocol for the dying phase.[4] Consensus-based guidelines have been developed. Lastly, support for healthcare professionals working in general practice and in hospitals by specialist palliative care consultation teams has been initiated.

2.2 Education on palliative and end-of-life care

Studies performed in the United Kingdom, Switzerland, Germany, and the United States of America have shown that medical students do not feel prepared and lack essential knowledge and skills to provide palliative or end-of-life care.[27-30] The quality of palliative care or end-of-life care education in the compulsory medical curricula has been evaluated in several European countries. These evaluations have led to recommendations to change compulsory curricula, for example by adding internships in hospices and teaching more theory about care for patients in the palliative phase.[28-33] A systematic review published in 2015 demonstrated that compulsory palliative or end-of-life care education varies in quantity and quality across European countries. The authors advised education programmers to include interdisciplinary education and to integrate palliative care education longitudinally through the medical curricula.[34]

The generalist plus specialist palliative care model requires that all healthcare professionals should at least be educated to provide palliative care on a generalist level.[22, 23] In 2009, centres of expertise in palliative care in the Netherlands published their assessment on palliative care in general education of healthcare professionals. Medical curricula were not reviewed. They found only few pre-defined endpoints, even for education for medical specialists in training.[35] Competencies for healthcare professionals working in palliative care were formulated in the COMPARE! Project, which was finished in 2013.[4, 36] A Dutch study among nurses demonstrated that 75% felt they need more education about subjects related to care for the dying. Subjects they most needed education on were knowledge of dying in other cultures; juridical aspects of euthanasia and assisted suicide; palliative sedation; providing support in coping with approaching death or saying goodbye; and decision-making at the end of life.[37] Knowledge and skills regarding palliative care of Dutch medical doctors had not been assessed in detail yet. A study from 2009 showed that 30% of Dutch medical doctors have insufficient knowledge about pain treatment.[4] Medical doctors often consult a colleague or pharmacist for complex cases of pain; 40% reported never having consulted a palliative care consultation team. Additional education about the use of opioids, pain treatment and palliative sedation was appreciated by 83% of the medical doctors in this study.[38]

The *Palliantie* programme characterised palliative care education as one of three main pillars in improving palliative care.[26] IKNL indicated that palliative care generalists lack knowledge and skills regarding palliative care. Barriers to providing quality palliative care were, amongst others, that healthcare professionals did not identify the palliative phase, did not perform advance care planning, and had limited expertise in generalist palliative care.[39] Generalist healthcare professionals should be educated in how to identify patients with palliative care needs. Using criteria for referral to specialist palliative care, or using tools such as the Surprise Question, can help to timely identify patients with palliative care needs.[40]

3. IDENTIFICATION OF PATIENTS WITH PALLIATIVE CARE NEEDS

Early identification of patients who may benefit from a palliative care approach is essential in achieving better quality of life.[41] There are several approaches that are helpful to identify patients with possible palliative care needs:

- Recognition of illness trajectories in palliative care (see 3.1)
- Recognition of trigger moments (see 3.2)
- Estimation of the patient's functioning and other clinical characteristics (see 3.3)
- Estimation of life expectancy (see 3.4)
- Use of the Surprise Question (see 3.5)
- Use of tools combining identification methods (see 3.6)

3.1 Recognition of illness trajectories in palliative care

Murray et al. described trajectories of functional decline of three main illness categories (Fig. 1).[42] In trajectories of incurable cancer, patient functioning remains fairly stable for weeks to years until a steep decline occurs in the last phase of life. During the stable phase, palliative care can prepare patients and their family for the last phase of life. The second category of trajectories includes functional decline with intermittent serious episodes, such as exacerbations of chronic obstructive pulmonary disease and heart failure. The patient's functioning can improve after each episode with adequate treatment, but the level of functioning will not be at the same level as before the episode. At some point, a patient will not be able to recover from the exacerbation because of organ failure, resulting in rapid decline and death. Palliative care can prepare patients and their family for the last phase of their disease trajectory when they reach the terminal stage of their condition, e.g., GOLD stadium IV in patients with chronic obstructive pulmonary disease, or NYHA class IV in patients with heart failure. The third category of trajectories concerns frailty and dementia, characterised by a gradual functional decline, leading to death from old age or frailty of the brain and other organs. Since these trajectories can take years, there are several possibilities to timely prepare patients and their families from the moment of diagnosis of dementia, or when functional decline presents.

Murray also graphed the trajectory of multidimensional palliative care needs for these three disease trajectories: physical, social, spiritual, and psychological.[44]

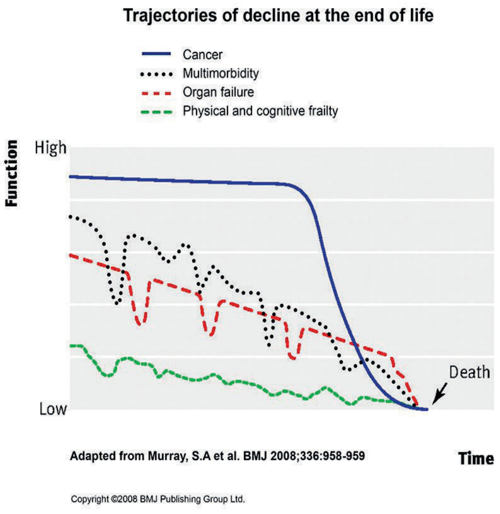

Fig. 1. The three main trajectories of decline at the end of life. From Murray S A, Sheikh A. Care for all at the end of life BMJ 2008; 336 :958, Figure 1.[43]

The palliative care "trajectory" model by Lynn and Adamson shows three phases within a palliative care trajectory (Fig. 2):

- disease-modifying phase, in which treatment is directed at slowing down the incurable disease;
- symptom-management phase, in which treatment is aimed at symptom-relief and supportive care;

- terminal phase, which is multi-dimensional care in the dying phase including bereavement care.[45]

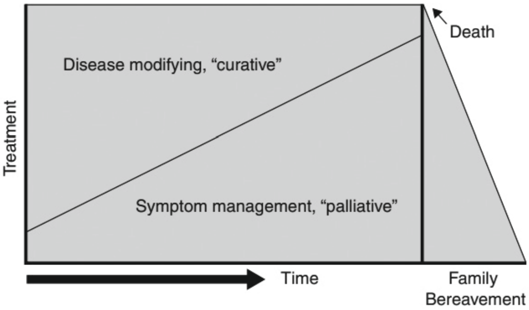

Fig. 2. A trajectory model of care. From Lynn, J. and D. M. Adamson (2003). Living Well at the End of Life. Adapting Health Care to Serious Chronic Illness in Old Age. RAND Health. Santa Monica, United States of America: 18, Figure 2. The Older "Transition" Model of Care Versus a "Trajectory" Model.[46]

This model provides an easy way to understand how a treatment trajectory gradually becomes more focused on supportive care and eventually on bereavement care. The model can be applied to many life-shortening conditions. There are however some exemptions. For instance, illness trajectories of patients with a haematological malignancy are more complex and the timing to assess palliative care needs can be difficult.[47] Haematological malignancies follow unpredictable trajectories which require very toxic curative treatments. In other words, patients not only have a high risk to die of their illness, but also of treatment. Along the illness trajectory, treatment is often with curative until the last days before death.[48]

3.2 Recognition of trigger moments

Illness trajectories and functional decline are accompanied with healthcare transitions, such as increased healthcare utilization and unplanned hospitalisations.[49, 50] Such trigger moments can be used to identify patients with palliative care needs.[51, 52] Trigger moments occur for example when cancer becomes incurable, or when patients and family receive bad news. Palliative crises can occur as trigger moments as well: patients suffer from uncontrollable symptoms or acute severe symptoms; family caregivers are exhausted; and local healthcare services provide insufficient palliative care. Trigger moments are not only crucial for assessing and treating the current problem but can also indicate that a patient is deteriorating. An emergency department visit is such a trigger.[53] The top five reasons patients in the palliative phase visited the emergency department in Ontario in 2002-2005 were abdominal pain, lung cancer, pneumonia, dyspnoea and malaise and fatigue.[54] Grudzen et al.'s randomised controlled trial in 136 patients with advanced cancer who visited the emergency department studied the effect of emergency department-triggered palliative care. They found that patients who had received palliative care triggered by the visit had a better quality of life than patients who received standard care.[55]

3.3 Estimation of the patient's functioning and other clinical characteristics

To support healthcare professionals in estimating the life expectancy of their patients, it may be helpful to know which factors predict approaching death. Predictors of approaching death can function as triggers for initiating a palliative care approach.[56] A predictor that is easy to use is poor performance status (measured using, for example, the European Cooperative Oncology Group (ECOG) Performance Status, World Health Organisation (WHO) Performance status or Karnofsky Performance Score), which is predictive of approaching death in patients with terminal cancer.[57-60] The ECOG performance status, depicted below, is scored by the patient's clinician with a score from 0 to 5 and is mostly used by clinicians to decide if the patient is fit enough to undergo systemic treatment. Poor performance is usually defined as an ECOG performance score of 3 and 4.[61]

Table 1. ECOG performance status[60]

Grade	ECOG performance status
0	Fully active, able to carry on all pre-disease performance without restriction
1	Restricted in physically strenuous activity but ambulatory and able to carry out work of a light or sedentary nature, e.g., light housework, office work
2	Ambulatory and capable of all selfcare but unable to carry out any work activities; up and about more than 50% of waking hours
3	Capable of only limited selfcare; confined to bed or chair more than 50% of waking hours
4	Completely disabled; cannot carry on any selfcare; totally confined to bed or chair
5	Dead

Apart from poor performance status, the occurrence or worsening of a number of symptoms in the palliative phase can be predictors for approaching death: anorexia, weight loss, dyspnoea, confusion and cognitive decline.[62-64] Prognostic models are more complex and including several clinical predictors can help clinicians assess whether patients have a short estimated life expectancy.[56, 65] Examples are the Palliative Performance Scale, Palliative Prognostic Index, Palliative Prognostic Score, Glasgow Prognostic Score and Chuang Prognostic Scale.[66-70] Most of the aforementioned prognostic models include many predictors of approaching death, which may be unpractical in daily practice.

Using predictors or prognostic models for approaching death to identify patients with palliative care needs can be helpful near the end of life to urgently arrange appropriate care. However, approaching death usually means death within three months. Predictors for approaching death are therefore less helpful in early identifying palliative care needs, because the opportunity to timely prepare patient and family for the end of life is missed out.

3.4 Estimation of life expectancy

Estimating the life expectancy of patients can help clinicians to become aware of possible palliative care needs and to determine which treatments are appropriate.[62] Clinicians can ask themselves a temporal question: "How long will this patient live?", which is answered with a number of time units (for example, 10 months). The temporal question is considered a simple way to formulate estimated survival. However, temporal predictions are often too optimistic and not very accurate.[71] A probabilistic question, "What is the chance that this patient survives the following hours, days, weeks, months, or year?", is more accurate, but more difficult to interpret.[56, 72] Moreover, clinicians are hesitant to estimate the patient's life expectancy, because it may feel definitive and as if one provides a guarantee.[56]

3.5 Use of the Surprise Question

The surprise question, "Would I be surprised if this patient dies within one year?", is a tool to early identify patients who may benefit from palliative care.[73] If the answer to the surprise question is "No, I would not be surprised", assessment of palliative care needs should be conducted. The surprise question is asked and answered by the clinician. The surprise question is not primarily meant to estimate survival within one year, but it combines a clinician-estimated probability of death during the following year to identify those who are currently in need of palliative care, with a gut feeling.[73-75] Time frames other than death within one year (e.g., 6 months, 3 months, 1 month, or 1 week) can be used to determine the urgency of palliative care and what care should be aimed at, for example, supportive care, hospice care or terminal care.[76] Systematic reviews and meta-analyses show that the surprise question has a c-statistic for one-year mortality ranging from 0.512 to 0.822 with an accuracy of 75%. However, the surprise question lacks sensitivity and positive predictive value (67% and 37%, respectively).[77, 78] The surprise question might perform better when predictors of approaching death are added.[78] No studies are conducted to test whether the surprise question adequately identifies patients with palliative care needs. Nonetheless, use of the surprise question is still recommended in clinical guidelines, such as the Netherlands Quality Framework for Palliative Care.[2]

3.6 Use of tools combining identification methods

The Netherlands Quality Framework for Palliative Care advocates that criteria for palliative care case finding should become part of the care process. These criteria include trigger moments, predictors for approaching death, and the surprise question.[2, 40] Several screening tools are developed that combine the aforementioned ways of identifying patients with palliative care needs. Most of these tools are tested in patients with cancer, but there are also tools for patients with heart failure, chronic obstructive pulmonary disease, and frailty. There are adjusted versions for various healthcare settings as well. Screening tools identifying patients with palliative care needs are the Supportive and Palliative Care Indicators Tool (SPICT), Necesidades Paliativas (NECPAL) identification tool, Golden Standards Framework—Proactive Identification Guidance (GSF-PIG), Radboud indicators for Palliative Care Needs (RADPAC), and a Centre to Advance Palliative Care's checklist.[49, 50, 79-81] A recent systematic review on palliative care needs screening tools in primary care also included the Palliative care: Learning to Identify in people with intellectual disabilities (PALLI) and the 'Rainoe tool'.[82] In the Netherlands, the SPICT and RADPAC are most frequently used, which both combine the surprise question, trigger moments and clinical indicators.[2] In a more recent version of the SPICT, the surprise question was removed because studies showed its test performance was limited in patients with diseases other than cancer.[77, 78]

4. ASSESSMENT OF PALLIATIVE CARE NEEDS OF PATIENTS AND THEIR FAMILY

After identification of patients and family with palliative care needs, discussions about their wishes regarding the last phase of life, and comprehensive assessments of the physical, psychological, social, and spiritual dimensions should take place across the illness trajectory.[2, 83] This section demonstrates the assessment of palliative care needs and information needs (4.1), and the importance of early discussion of the end-of-life preferences of patients and their family (4.2).

4.1 Assessment of palliative care needs

Assessment of patient-reported symptoms in palliative care is beneficial since it improves quality of life, reduces emergency department admissions, and may even improve one-year survival, as is shown in Basch et al.'s randomized controlled trial in 766 patients with advanced cancer.[84] Many tools have been developed to structure assessments of problems and symptoms in the four dimensions of palliative care: the physical, psychologic, social and existential.[83, 85, 86] Most multidimensional assessment tools are developed for assessments in patients with cancer.[86] The following paragraph focusses on the tools that are used most frequently in the Netherlands.

In 2018, IKNL published a selection of measurement instruments in palliative care that are validated in Dutch and validated for use in palliative care.[2, 87] These instruments are of multidimensional nature:

Table 2. List of multidimensional instruments for assessing palliative care needs, derived from the Dutch quality framework on palliative care.[2]

Instrument	Target population	Aim	Dimensions addressed			
			Physical	*Psychological*	*Social*	*Spiritual*
Lastmeter[88] *(Distress Barometer)*	Patients with cancer	Signalling experienced burden of disease	x	x	x	x
USD[89]	Patients in the palliative phase	Signalling and monitoring of symptoms	x	x		
CRQ[90]	Patients with chronic lung disease	Monitoring of quality of life	x	x		
CaReQoL CHF[91]	Patients with heart failure	Monitoring and targeted assessment of quality of life	x	x		
GFI[92]	Elderly	Targeted assessment of frailty in elderly during treatment decision-making	x	x	x	
G8[93]	Elderly patients with cancer	Targeted assessment of frailty in elderly during cancer treatment decision-making	x	x		

List of abbreviations: USD: Utrecht Symptom Diary; CRQ: Chronic Respiratory Questionnaire; CaReQoL CHF: Care Related Quality of life voor Chronisch Hartfalen; GFI: Groningen Frailty Indicator; G8: Geriatric Assessment 8.

The Edmonton Symptom Assessment System (ESAS), developed by Bruera et al. in 1991, was the first tool to use numeric rating scales (from 0, no complaints, to 10, worst complaints) to assess and monitor patient-reported symptom burden for symptoms that are common in the palliative phase: pain, tiredness, nausea, depression, anxiety, drowsiness, decreased appetite, poor sense of well-being, shortness of breath.[94] The ESAS has been widely studied since 1991: from the trajectories of symptom burden, to its role as a trigger in identifying palliative care needs and its integration into electronic patient files.[95] Symptom scores of ≥4 are considered clinically relevant, warranting more comprehensive assessment and treatment, and scores of ≥7 are considered as serious burden.[96] Several studies conclude that a difference of one point on the numeric rating scales is a clinically relevant change in symptom intensity.[97, 98]

The ESAS was translated into more than twenty languages, including Dutch.[89] The validated Dutch version, the Utrecht Symptom Diary (USD), includes numeric rating scales for common problems. Also, patients can fill out which complaint(s) or problem(s) should be addressed first. The USD addresses physical and psychological symptoms or problems. To also acquire an assessment of the social and spiritual dimensions, researchers of the Dutch academic hospice Demeter and the University of Humanistics developed the

USD – 4 dimensional (USD-4D).[99] The USD-4D is congruent with the Ars Moriendi model developed by Carlo Leget, which is depicted as a diamond existing of five continuums that represent aspects of dying.[100] The content of the USD-4D is validated from the perspective of patients.[99]

According to IKNL's selection in Table 2, only the Lastmeter would suffice in identifying patients who have palliative care needs in all four palliative care dimensions. The new USD-4D will probably be added to this list as it is content-validated and includes the four palliative care dimensions.[99]

4.2 Assessment of information needs

It is necessary to assess the needs of patients and family in order to support them. A study using the Dutch Potential problems and Needs for Palliative Care (PNPC) questionnaire found that patients indicate different items they experience as a problem and items they wanted professional attention for.[101] The authors concluded that problems are not the same as unmet palliative care needs. Assessment of palliative care needs of patients and their family should also include assessment of their information needs, and of how they cope with their prospects. Additionally, patients and their family need support in remembering what was explained during consultations.[102-106] While patients and their family have information needs about palliative care, they are often unaware of the questions they can ask during palliative care consultations.[106, 107] Lack of knowledge about palliative care and insight into their information needs impedes their sense of self-efficacy and may result in a sense of loss of control over their lives.[108, 109] For healthcare professionals, it is essential to communicate effectively to acquire insight in the palliative care and information needs.[110-112] Information-provision to patients with an advanced disease and their family stimulates self-management and supports coping with the disease now and in the future.[113] A study by Temel et al. in 2017 showed that end-of-life preferences were discussed more often in patients who received palliative care plus standard care, versus standard care alone. This implies that application of a palliative care approach encourages discussions about the needs, wishes and values of patients and their family.[114] During palliative care needs assessments, generalist palliative care healthcare professionals often do not inquire their patients thoroughly enough. They mostly focus on the physical dimension, and often do not assess information needs.[115, 116]

Question prompt lists are structured lists with sample questions patients and their family may ask during conversations with their clinician and to share information needs.[117] Patients and their family are asked to prepare their palliative care consultation by indicating which questions they would like to ask. Most question prompt lists are used in patients with (advanced) cancer.[118-130] Studies about these oncology question prompt lists have shown that patients find question prompt lists helpful, that they ask more questions, especially about prognosis or end-of-life issues, that they were more satisfied with the consultation, and that healthcare professionals provide more information.[117, 124]

Clayton et al. developed a question prompt list for use in palliative care. They asked input from clinicians, patients, and their family.[112] In their randomised controlled trial, they found that patients and family who had used the question prompt list asked twice as many questions compared to those who had not. They asked more questions about prognosis and end-of-life issues. Less information needs about the future were left unaddressed. On average, the consultations were 31 minutes longer when a question prompt list was used. There were no differences in satisfaction with care or anxiety scores between patients who did and did not use the question prompt list.[131] The question prompt list of Clayton et al. can be used by both patients and their family. Hebert et al. developed a question prompt list focused on family of patients in need of palliative care. They asked input from family and clinicians to compose the question prompt list. Their pilot study demonstrated that both family and clinicians found it useful in practice.[132]

In 2013, the hospital palliative care consultation team of Leiden University Medical Center constructed a conversation guide that combines the Utrecht Symptom Diary with an adapted Dutch version of the question prompt list by Clayton et al. This conversation guide is called Leiden Guide on Palliative care (LGP). The LGP is handed out to patients and their family as preparation for consultations with the palliative care consultant. The use of the LGP has not been evaluated before.

5. CONTEXT OF THIS THESIS

Since its start in 2011, the Center of Expertise in Palliative Care (CEPC) of Leiden University Medical Center hosts a specialist palliative care consultation team that holds the responsibilities of a specialist palliative care team as described by Henderson et al.[23, 133] The core activities of the CEPC are aimed at integration of care, education, and research; empowering generalist healthcare professionals; and supporting patients and their family. The palliative care consultation team uses the four-dimensional palliative care approach including the physical, psychologic, social, and existential dimensions in all their activities. The CEPC has formulated the following points of focus:

- Transmural and interdisciplinary collaboration between all care settings (home, hospice, nursing home and hospital)
- Timely identification of patients with palliative care needs
- Advance care planning
- Empowering patients and their family
- Two-track approach: the integration of a palliative care approach into standard care

6. AIMS AND OUTLINE OF THIS THESIS

The studies presented in this thesis reflect bottlenecks that were identified by our palliative care consultation team through their clinical experience since 2011. Additional bottlenecks were identified through quality-of-care evaluations and surveys that were held in Leiden University Medical Center to assess barriers and facilitators to hospital palliative care.[133] Important bottlenecks that were subject to research and are included in this thesis were:

- Palliative care education needs expressed by generalist clinicians
- Unnecessary and preventable healthcare transitions to the emergency department (ED)
- Patients and family being unaware of their palliative care and information needs

The aim of this thesis was to find opportunities to improve proactive palliative care by providing insight in:

- Current Dutch medical education;
- Timely identification of patients with palliative care needs; and
- Ways to support patients, their family, and clinicians to tailor conversations about palliative care.

The studies in this thesis included input from patients and their family, and from professionals from the field of education, clinical practice, and research.

The research objectives of the studies in this thesis were the following:

1. To assess the extent to which end-of-life care is taught at medical schools in the Netherlands and to find opportunities to improve Dutch medical curricula.
2. To explore palliative care needs and the extent of proactive care in patients with advanced cancer who visited the ED in the last three months of their lives.
3. To describe the end-of-life trajectory and quality of care of patients with a haematological malignancy who visited the ED in the last three months of their lives, compared to patients with advanced cancer.
4. To evaluate the performance of the surprise question to identify palliative care needs in patients with advanced cancer visiting the ED.
5. To explore the association between symptom burden and information needs of patients referred to a hospital palliative care consultation team using the Leiden Guide on Palliative care (LGP).
6. To evaluate and further develop the question prompt list of the LGP to prepare the question prompt list for use by generalist palliative care clinicians.

Chapter 2 (aim 1) discusses the integration of end-of-life care in Dutch medical curricula. End-of-life care was chosen instead of palliative care because sufficient end-of-life care education is vital to improve palliative care education. Based on literature review, a checklist was made comprising of elements that are essential in undergraduate medical education. Using this checklist, we assessed the National Blueprint on Medical Education, the bachelor, and master curricula of all eight medical faculties of the Netherlands and their elective courses in 2016. In **Chapter 3** (aim 2), disease and visit characteristics are described of 420 patients with advanced cancer visiting the ED between 2011 and 2013. Possible predictors for approaching death were analysed to support screening for urgent palliative care needs at the ED. **Chapter 4** (aim 3) presents the end-of-life trajectories of 78 patients with a haematological malignancy visiting the ED in the last 3 months of life. The quality indicators of Earle et al. were used to describe the quality of end-of-life care provided to patients with a haematological malignancy.[13] A comparison was made with 420 patients with a solid tumour. The test characteristics of the surprise question are studied in **Chapter 5** (aim 4). An observational prospective cohort study was conducted in 245 patients with advanced cancer who visited the ED in 2013 to 2014. Other predictors for approaching death were tested, and we evaluated whether addition of these predictors improved the test characteristics of the Surprise Question. **Chapter 6** (aim 5) provides an overview of the symptom burden and information needs of 321 patients referred to a hospital palliative care consultation team, using data from Leiden Guides on Palliative Care collected between 2013 and 2018. The association between symptom burden and information needs was studied. The evaluation and further development of the Leiden Guide on Palliative Care was carried out from 2017 to 2019 and is described in **Chapter 7** (aim 6). Qualitative methods including thematic analysis of 35 semi-structured interviews and open coding of 33 recorded consultations were used to acquire input from patients, their family, and clinicians. **Chapter 8** concludes this thesis with a general discussion of how our findings can improve proactive palliative care, and provides recommendations for future research, education, clinical practice, and policy.

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