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

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# CHAPTER 8

## General discussion

This chapter consists of five parts. Part 1 provides the main findings of the studies presented in this thesis. Part 2 reflects on the methodologies used in our studies. Part 3 describes the implications of the outcomes of this thesis regarding a proactive approach in palliative care. Part 4 includes recommendations for future research and Part 5 provides recommendations for education, clinical practice, and policy.

## 8.1 MAIN FINDINGS

### Objective 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.

**Chapter 2** describes a cross-sectional study assessing the extent to which end-of-life care was part of Dutch medical curricula. This study was focused on end-of-life care as essential part of palliative care. The study was conducted during the academic year of 2015-2016. A checklist including the essential domains of end-of-life care education was constructed based on literature. The study demonstrated that the national blueprint on medical education included four of the five domains of end-of-life care. One faculty taught an elective course that included all essential domains. None of the eight medical faculties taught all domains of end-of-life care; these domains were taught in the light of other courses but did not specifically address end-of-life care.

### Objective 2: To explore palliative care needs and the extent of proactive care in patients with advanced cancer who visited the emergency department (ED) in the last three months of their lives.

Knowledge about problems leading to visits to the Emergency Department (ED) in patients in the last three months of their lives and about who are at high risk of approaching death is relevant in ED-triggered palliative care. In **Chapter 3**, we conducted a mortality follow-back study in 420 patients with advanced cancer who visited the ED up to three months before they died. Our study showed that their care was often still focused on disease-modification. Only a few patients had limitations on life-sustaining treatments. This may have led to a high percentage of hospitalisations and in-hospital deaths in this study. Factors associated with approaching death were lung cancer, neurologic deterioration, dyspnoea, hypercalcemia, and jaundice.

## Objective 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.

Patients with a haematological malignancy often receive more aggressive end-of-life care than patients with a solid tumour. Insight into cues for proactive care can help improving ED-triggered palliative care in patients with a haematological malignancy. **Chapter 4** presents a mortality follow-back study in 78 patients with a haematological malignancy and 420 patients with a solid tumour visiting the ED in the last three months of life. Before their ED-visits, patients with a haematological malignancy had less often discussed limitations on life-sustaining treatments. Since their ED-visit, patients with a haematological malignancy were more often hospitalised after their ED-visit, received more aggressive end-of-life care, and more often died in-hospital, in the intensive care unit or in the ED, compared to patients with a solid tumour.

## Objective 4: To evaluate the performance of the surprise question to identify palliative care needs in patients with advanced cancer visiting the ED.

The Surprise Question (SQ), ‘‘Would I be surprised if this patient died in the next 12 months?’’, is an instrument to identify patients with palliative care needs. A meta-analysis of Downar et al. demonstrated that the SQ lacks sensitivity and may be more accurate when combined with other indicators of palliative care needs. **Chapter 5** describes an observational cohort study in 245 patients with advanced cancer visiting the ED in 2013 and 2014. The SQ had the following test characteristics: sensitivity of 89%, specificity of 40%, positive predictive value of 85%, negative predictive value of 50% and a c-index of 0.56. In patients in whom physicians would not be surprised if they died within one year, ECOG performance status 3-4 was an independent predictor for approaching death. Addition of ECOG performance status 3-4 as a second step to the SQ improved the c-index (0.65), specificity (92%) and positive predictive value (95%) at cost of sensitivity (40%) and negative predictive value (29%).

## Objective 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).

The LGP is a conversation guide on palliative care consisting of two parts. The first part comprises the Utrecht Symptom Diary, a translated and adapted Edmonton Symptom Assessment Scale.[1] The second part is a question prompt list on palliative care, a Dutch adaption of the version developed by Clayton et al.[2] The relationship between patient-reported symptom burden and information needs has not been studied before. **Chapter**

**6** includes an observational study in 321 patients referred to a palliative care consultation team who had used a LGP between 2013 and 2018. We found that patients reported highest median symptom burden for *Fatigue* (7; range 4-8) and *Less appetite* (6; range 3-9). Most information needs were about *Fatigue* (68.0%), *Possibilities for managing complaints in the future* (68.0%) and *Complaints expected for the future* (67.3%). Patients had significantly more information needs about symptoms for which they reported clinically relevant burden, or which they had prioritised. However, patients who reported mild symptom burden, also regularly indicated that they wanted information about that symptom. Patients in the late palliative phase more often wanted information about how they can manage care at home or in a hospice, while patients in the early palliative phase wanted more information about how treatment can affect their quality of life.

### Objective 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.

In **Chapter 7**, we performed a mixed-methods study in 2017-2018 to evaluate use of the question prompt list of the LGP and to further develop it using 35 interviews with patients, family, and generalist clinicians and 32 audiotaped consultations. Patients, family, and clinicians regarded the question prompt list as relevant. Patients and family explained that using the question prompt list before the consultation structured their thoughts and helped them ask their questions during consultations. It supported them to regain a sense of control. Although using the question prompt list could evoke strong emotions, they indicated that their real challenge was to accept being a patient in the palliative phase. Clinicians found that the question prompt list could support them as a reminder of discussion topics. During consultations in the hospital with palliative care consultants, topics patients and family had indicated were discussed frequently, but also topics aimed at (re)organising life at home were discussed.

## 8.2 REFLECTIONS ON THE USED METHODOLOGIES

In **Chapter 2**, a cross-sectional study was conducted to acquire an overview of the status of education of end-of-life care in Dutch undergraduate medical curricula. A checklist including essential domains of end-of-life care education was established based on literature review to assess the national blueprint on medical education and to form structured questionnaire to send to study coordinators. Using these methods, results of this study represent the state of education on end-of-life care in Dutch medical education in the academic year of 2015-2016 making use of internationally endorsed domains. Some participants indicated it was difficult to point out which curricular parts were actually about end-of-life care. They felt that end-of-life care, if taught, seemed to be intertwined with other topics. This may have biased the results in both positive and negative directions. To minimise this effect, all respondents were interviewed about their answers in the questionnaire. Data were provided of 15 out of 16 bachelor and master curricula in the Netherlands. Unfortunately, data from one master curriculum were not provided despite repeated reminders. Since data from the 15 other curricula were collected and analysed, this study still provides a reliable overview of end-of-life care in Dutch undergraduate medical curricula in 2015-2016. All elective courses were assessed by the researchers using the checklist. Any electives that were not found in study brochures were therefore not included, but it seems unlikely any electives were missed.

In **Chapter 3** and **Chapter 4**, we performed a mortality follow-back study in patients with advanced cancer or a haematological malignancy visiting the Emergency Department (ED) in the last three months of their lives in 2011-2013. A follow-back timeframe of three months was chosen because a life-expectancy of three months or less is an indication for referral to palliative-terminal care in the Netherlands. Including patients who died up to three months after their ED-visit gives pragmatic insight into the end-of-life trajectories of these patients, and into the intensity of care provided to them. Because we collected data retrospectively, there is a risk of registration bias and unmeasured confounding. Our study design choice for a mortality follow-up back study instead of a retrospective cohort study including all visiting the ED in 2011-2013 has important consequences. Since those who did not die within 3 months were not included, analysis of risk factors for approaching death after the ED-visit are only representative for those who will eventually die within three months.

In **Chapter 5**, the performance of the Surprise Question (SQ) in patients with advanced cancer visiting the ED is evaluated using a prospective observational design. E-questionnaires including the SQ were sent to attending physicians within one working day from the patient's ED-visit. Although e-questionnaires were sent as soon as possible, there might be some recall bias from attending physicians particularly remembering patients who were sicker than other patients. Patient data were retrospectively collected from their charts, which may have introduced bias by under-registration of characteristics and symptoms. Under-registration of symptoms that are prevalent in the palliative phase is possible because these symptoms are not routinely screened in our ED.

**Chapter 6** describes an observational study on symptom burden and information needs of patients referred to a hospital palliative care consultation team between 2013 and 2018 and who had used the Leiden Guide on Palliative care (LGP). In the LGP, the Utrecht

Symptom Diary precedes the question prompt list. Because of this order, patients may have indicated information needs about symptoms more frequently than information needs about other topics. This study included mostly patients with advanced cancer, reflecting a specialised setting of an academic medical centre. Therefore, caution must be taken when interpreting the results for patients with other diseases in the palliative phase. The LGP is selectively distributed by the palliative care consultants of Leiden University Medical Center, who estimate whether patients are fit enough to go through the LGP. If they already may be in the dying phase, the LGP is not handed out. This may have led to selection bias because the study lacks data from those in the dying phase and those who did not have enough energy to go through the LGP. In addition, it is possible that some patients did not receive or use the Leiden Guide because they were not emotionally ready to read about palliative care topics. Patients could decide themselves not to use (parts of) the LGP.

In **Chapter 7**, a mixed-methods research design was used to evaluate how the question prompt list of the LGP is used and could be further developed. Data from interviews with patients, family and non-specialist palliative care clinicians, and audiotaped consultations of our palliative care consultation team were included. The patients who were interviewed mostly had cancer. It is possible that patients with different diagnoses have other information needs. The included generalist (non-specialist) clinicians had not used the question prompt list before. Their responses in the interviews were therefore hypothetical and may differ from clinical practice.

## 8.3 IMPLICATIONS OF THE OUTCOMES OF THIS THESIS

The studies presented in this thesis address various themes within the broad scope of palliative care. The common theme explored is proactivity in palliative care, and how it can be improved. Opportunities are identified to improve a proactive approach in palliative care in good quality undergraduate medical education, empowerment of patients and family during palliative care consultations, timely identification of palliative care needs and in the use of a two-track approach for patients with unpredictable yet life-threatening diseases. This section includes four paragraphs:

1. Definition and meaning of proactive palliative care
2. Promoting knowledge and self-initiation
3. Intention to produce good results and avoid (future) problems
4. Thinking ahead to be able to act before things happen

The first paragraph explains more about what proactivity and proactive palliative care entail. The following three paragraphs elaborate on the characteristics of proactive palliative care that are derived from paragraph 1 and studied in this thesis.

### 8.3.1 Definition and meaning of proactive palliative care

Proactivity is an integral part of palliative care. When searching for the definition of proactivity in English dictionaries, the following definitions of '*proactivity*' can be found:

- *Taking action by causing change and not only reacting to change when it happens* (Cambridge dictionary)
- *Intending or intended to produce a good result or avoid a problem, rather than waiting until there is a problem* (American dictionary)
- *Taking action to make changes yourself rather than reacting to things that happen* (Business English dictionary)

From these definitions of proactivity, the following characteristics of a proactive person ('the actor') can be derived:

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- the actor must have **knowledge and self-initiation** to act himself and **take control**.
- the actor must have an **intention** to make a change to **have good results** or to **avoid problems**;
- the actor must **think ahead** to be able to act before things happen;

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The concept of proactivity is studied in-depth in management and business studies and can be regarded as a process in which goals are proactively set and strived for.[3] In health care, the concept of proactivity is not widely studied yet. Proactivity is mainly described as patient behaviour, a characteristic or behaviour of (successful) healthcare professionals and as health promotion.[4-8] In these studies, proactivity was defined as: anticipating in correcting problems before they "become insurmountable mountains"; information-seeking, advice-seeking, participating in decision-making, assertiveness towards healthcare professionals, actively taking care of one's health status, promoting health and wellbeing. 'The actor' in health care can refer to patients, their family, and clinicians.

Palliative care is deemed appropriate already early in the illness trajectory concurrent with life-prolonging treatments. Palliative care models such as illustrated by Murray et al. show that patients and family have care needs in physical, psychological, social, and spiritual domains during the whole illness trajectory (Fig.1 in Chapter 1).[9, 10] Palliative care integrated early into standard life-prolonging or even curative therapy creates the opportunity to support patients and family to express what they value in life and how they want to live their lives. In this way, appropriate care can be organised concordant with the patient and family's needs and wishes. They can timely prepare for the end of life. In scientific literature, proactive palliative care is often equated to early palliative care, and involves timely identification of patients with palliative care needs, proactive conversations about patients' and family's wishes about the end of life, patient empowerment and prevention of future problems.[11, 12] However, proactive palliative care not only refers to early palliative care, but is an appropriate approach along the whole illness trajectory. Sometimes, dependent on the illness trajectory, it is not possible to initiate palliative care early; in these cases, a 'late' proactive approach is also demanded to achieve person-centred and appropriate care.

Proactive palliative care includes actions such as goals-of-care discussions, multidimensional treatment of symptoms and supportive care of patient and family, multidisciplinary collaboration, and preventive medicine. Other aspects of proactive palliative care are communication with other healthcare providers about end-of-life issues and making and sharing proactive care plans.[13-18] Palliative care can therefore be considered as an active approach to care in the last phase of life with proactive characteristics. The 2017 Netherlands Quality Framework for Palliative Care indeed describes that one of the core values of palliative care is being proactive: *"Together with the patient and family, the physical, psychological, social and spiritual dimensions should be **proactively** assessed and documented for situations in which:*

- *normal, everyday attention is enough;*
- *there is a need for guidance or treatment;*
- *crisis intervention is necessary."*[19, 20]

In proactive palliative care, goals of care should be discussed in shared decision-making. Aligning with the 2002 World Health Organisation's definition of palliative care and the previously derived definition of proactivity, proactive palliative care has the following goals:[3, 21]

- *to produce a good result*, i.e., to improve or maintain quality of life and appropriate care.[22] Appropriate care is associated with good supportive care, care decisions including waiving or stopping treatment, sufficient symptom relief, care at home, following wishes of the patient, and effective communication (including advance care planning, right attitude, listening and informing).[23] To achieve this, palliative care should be of good quality and in line with preferences of patients and family, while taking into account the four dimensions of palliative care (psychological, social, physical and spiritual), and stimulate self-management of patients and family. To optimally benefit from palliative care, a palliative care approach should be integrated into standard care early in the disease trajectory. Along the whole illness trajectory, good quality palliative care is proactive rather than reactive. A proactive attitude is preferred to prevent problems and suffering in the (near) future.

- *to avoid (future) problems*, i.e., to avoid poor quality of the last phase of life. A poor quality of the last phase of life includes unnecessary symptom burden, caregiver burden and inappropriate care. Inappropriate care is associated with insufficient supportive care, overtreatment and insufficient symptom relief, hospital care, not following wishes of the patient, and poor communication (mainly informing insufficiently and not-listening).[23]

Taking the aforementioned concepts and definitions of proactivity and palliative care into account, the following themes can be identified, with the following recommendations articulated in this thesis:

| Theme | Subthemes addressed in this thesis |
|---|---|
| 8.3.2 Promoting knowledge and self-initiation in clinicians, patients, and family | 1. Good education for undergraduate medical students<br>2. Patient and family empowerment |
| 8.3.3 Intention to produce good results and avoid (future) problems | 1. Quality indicators for palliative care in patients with a haematological malignancy<br>2. Timely identification of palliative care needs: ED-triggered palliative care in patients with advanced cancer |
| 8.3.4. Thinking ahead to be able to act before things happen | 1. A two-track approach<br>2. Discussing future scenarios |

The next sections will discuss how the studies included in this thesis contribute to the concept of proactive palliative care, and which recommendations can be made based on this thesis.

## 8.3.2 Promoting knowledge and self-initiation in clinicians, and patients and family

### *1. Good education for undergraduate medical students*

*(partly adapted from de Bruin et al. NED TIJDSCHR GENEESKD. 2020;164:D4115)*[24]

In the Netherlands, provision of palliative care is organised following the generalist – specialist palliative care system.[25] This means that all clinicians should have at least basic palliative care competences. These responsibilities are described in the Netherlands Quality Framework for Palliative Care 2017.[19] Furthermore, a publication in JAMA about the need for appropriate palliative care during the COVID-19 pandemic, reminded that palliative care is a human right, and that patients without curative options should not be abandoned.[26] The study in **Chapter 2** addressed undergraduate medical education.

The study demonstrates that the 2009 Dutch national blueprint on medical education insufficiently mentioned end-of-life care, and none of the formal undergraduate curricula of the Dutch medical schools in the academic year of 2015-2016 offered all essential elements of end-of-life care education. The national blueprint on medical education is authoritative for the curricula for Dutch medical faculties and should therefore at least include the essential domains of end-of-life care, which were found using a literature review. Pieters et al. found that final year medical students indicated that various topics were insufficiently addressed in their curricula and 60% of them felt unconfident in providing palliative care.[27] In March 2020, the new blueprint on medical education was published.[28] The introduction of the blueprint stated that it aims to prepare medical students for the future, including challenges of ageing populations and multimorbidity. The definition of palliative care is added, and generalist palliative care is now anchored as basic knowledge any freshly graduated physician should have.

**Chapter 2** provides insight in how individual bachelor and master curricula in the Netherlands can improve their programmes so that young physicians are sufficiently prepared for clinical practice. Many efforts have been made to integrate palliative care into existing Dutch medical curricula. The Palliative care Alliance Sharing Educational tools for Medical student Competencies development (PASEMECO) project, listed six Entrustable Professional Activities (EPAs) for undergraduate medical education regarding palliative care that should be taught to all medical students.[29] These EPAs reflect which clinical activities young physicians can encounter in clinical practice. Additionally, the PASEMECO project offers an online toolbox with elements of palliative care education which are published on the Palliaweb website.[30] These elements are collected from all Dutch universities and are free to use by teachers.

This thesis only addressed undergraduate medical education. The O2PZ programme, which is supported by the Dutch government since 2019, aims at securing palliative care education at all educational levels in the Netherlands. In this programme, palliative care specialists, teachers and educationalists cooperate in developing education frameworks that provide an overview of all continuing education courses, designing and implementing education, and increasing the visibility of what is happening to optimise palliative care education.[31] In the O2PZ programme, the EPAs for undergraduate medical education formulated by the PASEMECO project are further developed and complemented.[32] Amongst many other activities, the O2PZ programme supports medical faculties in implementing palliative care education, so that their curricula meet the criteria of the blueprint.

Integration of palliative care and end-of-life care education into undergraduate medical curricula contributes to the preparation of future medical doctors to provide generalist palliative care. Promoting their knowledge and skills is a prerequisite for employing a proactive palliative care approach in clinical practice.

*2. Patient and family empowerment*

This paragraph demonstrates how this thesis articulates to the concept of patient empowerment as part of the person-centred care model. Proactive palliative care includes the improvement of patients and family's self-initiation: empowerment. Part of empowerment is the exploration of the values and needs of individual patients, which is also essential in person-centred care. Many definitions of person-centred or patient-centred care exist and are often used interchangeably. Little et al. identified core activities of patient-centred care:[30, 33]

- Exploring how patients experience their disease and illness, including their ideas and feelings about it, their expectations of the consultation and how their functioning is affected;
- Understanding the patient as a whole, including personal and developmental aspects and their context;
- Establishing a partnership with the patients, sharing problems, priorities, and goals of treatment, agreeing on the patient and clinician's roles, enhancing this patient-clinician relationship by sharing power and sustaining a relationship that is caring and healing;
- Promoting health, including enhancement of health, reduction of risks and the early detection of disease.

Person-centred care originates from care for people with a chronic illness, where planned care (i.e., proactive care) is preferred to reactive care because it creates more opportunities to provide appropriate care. A person-centred approach is then appropriate since the person himself is the expert of his own experience of being ill. It is patient-friendly to support them so that they can manage their needs in a way that fits their way of life and being best.[34] Person-centred care has favourable patient outcomes: patients have a better understanding of their illness, are more aware of their health and treatment options, feel more capable and confident to make decisions, and know more about symptoms.[34-36]

Person-centred care is a model of care that makes it possible to share knowledge, status, and decision-making in an equitable patient-clinician relationship. McWilliam et al. argue that these are elements that support the empowerment of patients and family.[37] The 'power' in a patient-clinician relationship changes when the 'expert' role of being ill is balanced between the clinician and the patient by sharing knowledge and experiences, and providing support. This is in line with the Netherlands Quality Framework on palliative care, which states that shared decision-making in palliative care is "*the continual process in which care is tailored to the personal situation and achievable values, wishes and needs of the patient and family*".[19] A power shift in the patient-clinician relationship towards patients and family is therefore desirable and warranted.

Patient empowerment is defined in various ways.[38] One of the definitions is that patient empowerment is "*an approach to health promotion involving patient autonomy, ensuring the patient is actively involved in their care, relying on an achievement of self-efficacy or having a sense of control in one's life*."[34] Empowering a patient can mean that the patient had been disempowered in the first place. Disempowerment may hinder their participation in decision making about the palliative phase. This experience of disempowerment corresponds with Rolland's 'crisis phase' of the 'Time Phases of Illness' in his integrative treatment model.[39] In this model, patients and family go through steps aimed at socialization to the new palliative diagnosis, which includes seven developmental tasks patient and family need to go through. Examples of these tasks are developing a meaning of the illness so that patients and family can stay in control; accepting that the illness is permanent; and learning to live with the life-limiting illness and problems associated with the illness. Patients and family are vulnerable during these developmental tasks and need advice from the clinicians to complete them. Effective communication which effectively enhances empowerment has several benefits for patients.[40] It is demonstrated that patients found they were better able to adapt to losses, including preparing for deterioration, management of personal issues and changing of priorities in life. They felt they were better capable of continuing their lives.[41]

The study in **Chapter 7** demonstrates that patients lost empowerment at the moment they found out they were in the palliative phase of their disease and that they felt more in control by using the question prompt list. They knew which issues were on their minds and which questions they wanted to ask. They felt they were better able to manage their lives because they could ask purposeful questions. As a result, the clinician's role shifts from discussing what they think are preferences of patients and family, to helping patients and family discovering their own preferences for care. **Chapter 6** shows that a question prompt list is a valuable addition to assessing symptoms, because it allows patients and family to not only indicate their current problems, but also their worries. These results show that our question prompt list enhances patient and family empowerment.

Non-specialist clinicians indicated in **Chapter 7** that using a question prompt list provides them with an overview of the information needs of patients and family and may help deepening their consultations. In this way, clinicians can give them tailored advise, so that patients and family can decide for themselves. This corresponds with Little et al.'s definition of patient-centred care: exploring patient's questions, understanding the patient within their context, enhancing the patient-clinician relationship and promoting health in line with the wishes of patients and family.[33] Furthermore, non-specialist clinicians indicated that the question prompt list can be helpful in their practice.

Because patient and family empowerment is desirable and warranted, the use of a question prompt list in palliative care is recommended. A question prompt list supports a proactive palliative care approach from a person-centred perspective, given that patient-related and clinician-related barriers are taken into account (Chapter 7, Table 3). This thesis demonstrates that the combination of the assessment of symptom burden and the assessment of information needs provides more opportunities for a person-centred and proactive approach than assessment of symptom burden or information needs alone. Use of the Leiden Guide on Palliative Care, which includes both, is therefore recommended in discussing and organising proactive palliative care.

### 8.3.3. Intention to produce good results and avoid (future) problems

*1. Quality indicators for palliative care in patients with a haematological malignancy*

Palliative care, especially early palliative care, leads to favourable outcomes compared to standard care in patients with advanced diseases, such as improved quality of life and relief of symptom burden.[42-49] These outcomes should be the goal of investing in producing good results and avoiding (future) problems. An example of a 'problem' that should be avoided is hospitalisation in the last months of life, because this can lead to aggressive or potentially inappropriate end-of-life care.[50] Research has shown that not all end-of-life hospitalisations are necessary.[51] Hospitalisations in the last three months of life can be avoided in 24%, according to general practitioners.[52]

Indicators for aggressive end-of-life care are described in more detail in **Chapter 1**. Indicators in the study on patients with cancer described in **Chapter 4**, by Earle et al., are the following:

- Receiving chemotherapy in the last 14 days of life;
- Starting a new chemotherapy regimen in the last 30 days of life;
- >1 emergency room visit in the last month of life;
- >1 hospitalisation in the last month of life;
- Admission to the intensive care unit in the last month of life;
- Death in an acute care hospital;
- Lack of admission to hospice;
- Admission to hospice <3 days before death.[53, 54]

In **Chapter 4**, the causes of death of patients with a haematological malignancy were disease progression (46%), treatment toxicity (40%), or both (9%), illustrating this particular end-of-life trajectory. These illness trajectories are often unpredictable with a sudden decline while patients are undergoing intensive treatment with curative intent. Because of the typical illness trajectory, one may wonder whether the common indicators of Earle et al. are appropriate for measuring the quality of end-of-life care in patients with a haematological malignancy.[55] Haematologists do not necessarily believe hospice admission early in the illness trajectory is an indicator of good quality of end-of-life care, because hospices or hospice care often cannot provide blood transfusions in cases of severe symptoms of anaemia, such as exhaustion, dyspnoea and bleeding.[56] More often, patients with a haematological malignancy will choose the possibility of blood transfusions over hospice care, risking of hospitalisations and admission to the ICU.[56] A study by Odejide et al. showed that haematologists found that the following quality indicators were considered acceptable by haematologists:

- Hospice admission > 7 days before death;
- No chemotherapy ≤ 14 days before death;
- No intubation in the last 30 days of life;
- No cardiopulmonary resuscitation in the last 30 days of life.[57]

These indicators for quality of care represent events that should be prevented, but do not explain what quality palliative care looks like. A two-track approach can support a proactive palliative care approach in haematology. Figure 1 in **Chapter 4** illustrates that curative care and palliative care should be concurrent because patients can have needs from both tracks. The curative track focusses on cure, whilst the palliative track focusses on the quality of life. Button et al. suggested an alternative disease trajectory model for haematological malignancies.[58] This model assumes that all patients with a haematological malignancy, no matter if the treatment is of curative or palliative intent, need a palliative care approach.

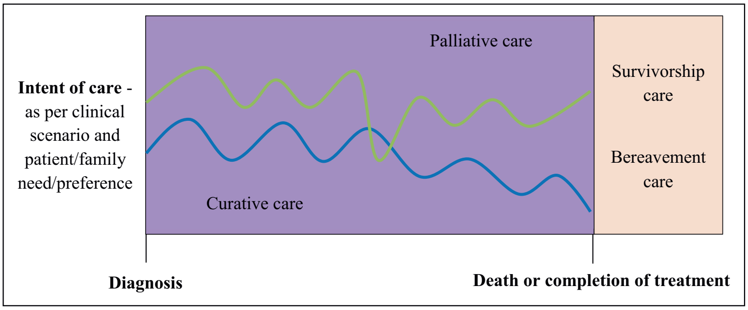

**Fig. 1.** Modified model of palliative care for people with a haematological malignancy. From Button E, Bolton M, Chan RJ, Chambers S, Butler J, Yates P. A palliative care model and conceptual approach suited to clinical malignant haematology. Palliative Medicine. 2019;33(5):483-485. doi:10.1177/0269216318824489[58]

The two-track approach in **Chapter 4** suggests a continuous evaluation of the goals of care. The cues for proactive care that were collected in **Chapters 3 and 4** can also be used for reviewing if the care delivered is concordant with the wishes of patients and family:

- Documentation of communication about the condition of the patient between a hospital clinician or palliative care specialist and the general practitioner of the patient. This communication could have occurred via a letter, telephone call or transfer notes.
- Documentation of proactive care plans, which could be the following documents:
  - Care plans for anticipating future symptoms or worsening symptoms;
  - Care plans directed at informing the general practitioner;
  - Care plans written by the palliative care consultation team;
  - Referrals to the palliative care consultation team.
- Documentation of limitations on life-sustaining treatments (i.e., no resuscitation, no ventilation, no admission to the intensive care unit).

In summary, commonly used indicators for quality of end-of-life cancer care may not be applicable for patients with a haematological malignancy and do not explain what quality proactive palliative care entails. Goal concordance, which is part of the two-track approach, can be an indicator of proactive palliative care and can be found in documentation in patient records.

*2. Timely identification of palliative care needs: ED-triggered palliative care in patients with advanced cancer*

In order to produce good results and avoid (future) problems (for definition, see 8.3.1), patients with palliative care needs should be timely identified. Early identification of palliative care needs can be difficult. Patients use acute healthcare resources more often in the last phase of life. Reasons for admission to an Emergency Department (ED) or hospital ward include serious symptom burden, not being able to manage at home, caregiver burden or lacking resources in the community setting.[59-62] Reaching out for acute medical help in the last phase of life may indicate disease progression and urgent palliative care needs. Because of this, events such as hospitalisations and ED-visits can function as triggers to consider if the patient can benefit from a palliative care approach.[63-67] **Chapter 3** illustrates that ED-visits triggered initiation of discussions on and documentation of limitations on life-sustaining treatments in many of the patients visiting the ED. This thesis addresses two elements of ED-triggered palliative care for patients with advanced cancer: identification of patients with urgent palliative care needs; and estimation of the urgency of palliative care needs using the Surprise Question and poor physical performance.

In **Chapter 3**, risk factors for approaching death were identified to support identification of patients with advanced cancer visiting the ED: a diagnosis of lung cancer, neurologic deterioration, dyspnoea, hypercalcaemia, and jaundice. Together with triggers for palliative care derived from previous literature, these risk factors were integrated into a risk assessment tool.[68] The use of these triggers can support ED-clinicians in choosing actions leading to appropriate care for vulnerable patients. These actions include goals-of-care discussions, assessment of patients and family needs, referral to the preferred place with appropriate care and referral to specialist palliative care for complex problems.

Although risk assessment tools for approaching death can be useful in the ED-setting to organise appropriate care,[69-71] they are not suited for early identification of patients with palliative care needs. The study in **Chapter 5** demonstrated that the surprise question was a predictor for death within one year with a high sensitivity and positive predictive value, and can be used as a screening tool to early identify patients with palliative care needs in patients with advanced cancer visiting the ED. Specificity and c-statistic improve if poor functional status (ECOG 3 or 4) is added as a second step following the surprise question. A similar effect has been demonstrated in a study in elderly visiting the ED demonstrated that adding physician experience in working years and the PREDICT criteria, which are triggers for palliative care, to the one-year surprise question, improved the c-statistic for predicting one-year mortality.[72]

The studies presented in **Chapters 3, 4 and 5** have confirmed that ED-visits have a trigger effect. Limitations on life-sustaining treatments were often discussed after a patient visited the ED, apparently giving food for thought about what appropriate care is. The use of risk assessment tools, and combining the surprise question with functional status, can support ED-triggered, appropriate and goal-concordant palliative care.

### 8.3.4. Thinking ahead to be able to act before things happen

*1. A two-track approach*

A two-track approach assumes that a palliative care approach is concurrent with a curative care approach. Using scientific literature, including Button's model of care, and clinical experience of clinicians who care for patients with a haematological malignancy, an integrated care model has been developed that assumes that care for patients with a life-threatening illness should *not only hope for the best, but also prepare for the rest* (illustrated in **Chapter 4**, Fig. 1).[58, 73-76] Goals-of-care discussions are an essential part of both tracks. Although **Chapter 4** focusses on the illness trajectory of patients with a haematological malignancy, it is probable that a two-track approach can also support patients with other serious illnesses that may still be curable. Examples are patients suffering from stroke or transient ischemic attacks, severe infections, or patients with organ failure waiting for transplantation.

Timely initiation of a two-track approach is challenging. Known barriers to initiate palliative care conversations indicated by clinicians are, amongst others:[77-79]

- Lack of time to conduct such conversations properly
- The patient's wishes and expectations are unknown
- Difficulties dealing with the needs of family
- Wishes and expectations of immigrant patients are unknown
- End-of-life conversations can trouble the clinician-patient relationship
- Feeling uncomfortable or unprepared to conduct such conversations.

It seems that training and gaining experience in palliative care conversations can facilitate initiation of those conversations and the use of a two-track approach. After implementation of the serious illness communication programme of Paladino et al., non-specialist palliative care clinicians were more aware of the necessity to initiate serious illness conversations early.[80] They initiated conversations earlier in the illness trajectory, and conversations were more holistic and more multidimensional. They said they started to think more proactively. This study proves that the implementation of person-centred communication methods raises awareness among clinicians on the value of timely conversations about palliative care, and that these discussions are initiated earlier.

### *2. Discussing future scenarios*

From this thesis follows that clinicians should inform their patients to empower them and that clinicians have a professional responsibility to signal, explain, and document future scenarios. According to the Netherlands quality framework for palliative care, the discussion and reporting of current and future needs and wishes should be a standard part of proactive palliative care.[19] The study in **Chapter 7** revealed that patients often want to know about the future and that they do not know what the future holds for them. They are reliant on their clinicians to provide them this information in order to regain a sense of control over their care. A two-track approach demands a proactive attitude from the clinician. However, Slort et al. found that future scenarios were not anticipated by general practitioners during end-of-life conversations.[81] Flierman et al. demonstrated that hospital clinicians sometimes wait for patients and family to express their wishes and preferences for the future, and do not initiate the topic themselves.[82]

Some clinicians in the study in **Chapter 7** mentioned that the question prompt list may support them in explaining future scenarios to patients and family. Patient-reported outcome measurements (PROMs), such as the Edmonton Symptom Assessment System (ESAS), can support communication between patients, their family, and clinicians.[83] Brooks et al. demonstrated that the ESAS helped them to identify and set priorities for treatment, and guided the conversation with the clinician.[84] Handing out a palliative care PROM to patients and family can therefore be considered as a proactive action. In **Chapter 6**, the Leiden Guide on Palliative care, which includes the Utrecht Symptom Diary (a Dutch adaptation of the ESAS) and a palliative care question prompt list, was used for data collection. The study in **Chapter 6** provides insight into which the symptoms patients and family have questions about. It seems that patients and family use the question prompt list to indicate about which symptoms they worry, such as shortness of breath and pain. It is known that symptoms that patients prioritise are not necessarily the symptoms that cause the highest burden.[85] This demonstrates that discussions about future scenarios can be tailored to the patient and family by using specific PROMs for assessment of symptom burden and information needs. **Chapter 6** demonstrates that the information needs of patients and family can differ by the phase of their illness. For example, patients whose treatment was mainly aimed at symptom management had more often information needs about managing care at home.

Discussing future scenarios is indicated and warranted: patients and family want and need to be informed about the future. The addition of the question prompt list to a symptom assessment scale supports clinicians to also ask about the worries of patients and family and to explain future scenarios.

## 8.4. RECOMMENDATIONS FOR FUTURE RESEARCH

Recommendations for future research following from this thesis will be addressed in three paragraphs:

1. Promoting knowledge and self-initiation in clinicians, and patients and family
2. Intention to produce good results and avoid (future) problems
3. Thinking ahead to be able to act before things happen

### 8.4.1 Promoting knowledge and self-initiation in clinicians, and patients and family

*1. Good education for undergraduate medical students*

Internationally, assessments of undergraduate medical education have resulted in implementation of end-of-life care courses or internships in the formal medical curricula. In the United Kingdom, for example, the assessment from 1983 revealed that four medical faculties did not pay any attention to end-of-life care.[86] Thereafter, the British medical curricula were changed in 1994 and 2002 and are regularly evaluated ever since.[87-89] Switzerland and Germany made similar changes.[90-92] The study described in **Chapter 2** and the studies by Pieters et al. can be considered as baseline measurements of the integration of end-of-life care and palliative care in the Dutch medical curricula.[27, 29] To evaluate the effect of curricular interventions, it is preferable to measure the actual presence, knowledge, perceived importance and confidence again after implementation. An evaluation study on the presence of palliative care in the undergraduate medical curricula could be conducted by using a questionnaire or structured interviews among curricular programmers. Next, the effect of curricular changes should be measured using the methods of Chapter 2 or Pieters et al.[27] EPAs (see 8.3.2.1), and competencies that are now added to the updated blueprint on medical education, can be used as primary outcomes in a cross-sectional survey or interview study in medical students who are about to finish their undergraduate medical studies. In this way, actual competence and experienced competence can be measured in young medical doctors, and opportunities for improvement of undergraduate education on palliative care can be identified.

*2. Patient and family empowerment*

Patients and family indicated in **Chapter 7** that the question prompt list of the Leiden Guide on Palliative Care (LGP) increased their sense of control. Future research should be aimed at how much the sense of control of patients and family increases after using the LGP in terms of feeling empowered to manage their illness. Self-management can be considered as the last station in person-centred care, according to Pulverenti et al.:

**Fig. 2.** Person-centred care improves patient empowerment, which improves self-management in patients and family. Adapted from Pulvirenti et al.[34]

Lorig defined self-management as "*learning and practicing the skills necessary to carry on an active and emotionally satisfying life in the face of a chronic condition*".[93] The main goal of self-management interventions is supporting the patient to live and achieve those outcomes he or she wishes. Dineen-Griffin et al. created a model that supports clinicians in conducting self-management interventions during consultations in a person-centred way. Essential elements of this model are:

- Provision of effective self-management support
- Theoretical base to the intervention
- Face-to-face multicomponent intervention with primary care provider
- Tailored combination of self-management supporting strategies relevant to patient needs
- Ongoing follow-up (face-to-face, telephone)

Further research should investigate whether appropriate use of a question prompt list, according to the model by Dineen-Griffin et al., not just increases patient empowerment, but also self-management. A study on improving self-management by using a question prompt list can have a randomised controlled trial design, in which one group of patients receives and discusses a question prompt list, and the second groups receives a 'standard' palliative care consultation or conversation without a question prompt list. Both groups receive person-centred care according to Dineen-Griffin's essential elements. The primary outcome would be patients and family's self-management. In this way, the value of a question prompt list on self-management of patients and family in the context of person-centred care can be determined.

A review by Wakefield et al. suggested that a patient satisfaction questionnaire may be a valuable addition to a question prompt list.[40] Further research can include the addition of patient satisfaction to the LGP, and be aimed at if this addition can improve person-centred care, patient empowerment and self-management. A study on an addition to the LGP could be an evaluation study including semi-structured interviews or questionnaires among patients and family.

Clinicians indicated in **Chapter 7** that the LGP can support palliative care consultations. However, for purposes to study whether non-specialists would support the use of the LGP, these clinicians had not used the LGP before. In advance of implementation of the LGP in several non-specialist settings, first a pilot study should be conducted among, for example, general practitioners to study the feasibility of using the LGP in their clinical practice. This pilot study can have a participatory action research (PAR) design. Using PAR, a working method can be developed using quantitative and qualitative research methodologies while improving care activities.[94] PAR includes the execution of action cycles, during which the working method can be refined, tested, and evaluated. PAR supports developing a working method in specific settings, which may be helpful in the complexity of care settings. Next, a cluster randomised trial in general practices can demonstrate whether the LGP improves 1) patient outcomes, such as quality of life, satisfaction, information needs and symptom burden, and 2) quality of palliative care and end-of-life care, using outcomes like quality indicators and goal concordance.

The LGP is mostly studied in patients with cancer. Further research involving the LGP should also include patients with non-cancer diseases to evaluate whether use of the LGP is suited in patients with a non-cancer diagnosis. This includes repeating the study presented in **Chapter 6**, which provides an oversight of symptom burden an information needs of patients of a palliative care consultation team of an academic medical centre, in another cohort of a palliative care consultation team. In this way, insight about symptom burden and information needs of patients with other illness trajectories can be provided. This study design can also be used to study symptom burden and information needs in patients in care settings other than the hospital, such as in general practice and in nursing homes.

The research suggestions described above concern the LGP, but also apply to palliative care question prompt lists in general. To support future research on question prompt lists in palliative care, McDarby et al. recently composed a research agenda concerning the use of question prompt lists in outpatient palliative care.[95] The authors state that more knowledge and insights are needed on five questions:

- which patient populations with palliative care needs will use and benefit from using a question prompt list?
- what is the right timing of providing a question prompt list and how could a question prompt list be provided best in the context of outpatient palliative care consultations?
- which patient and family outcomes are addressed by using a question prompt list in outpatient palliative care, and how are these outcomes addressed?
- which characteristics of a question prompt list on palliative care contribute to the best benefits to patients and families in outpatient palliative care?
- what are the potential benefits of using a question prompt list for palliative care clinicians and healthcare organisations?

It is possible that the answers to each research question differ for the variety of question prompt lists, care settings and patient populations. It is important to study which situations demand certain kinds of question prompt lists. Additionally, it seems plausible that the same research questions hold for the use of question prompt lists inpatient palliative care, and that the answers may differ from outpatient palliative care.

### 8.4.2 Intention to produce good results and avoid (future) problems

*1. Quality indicators for palliative care in patients with a haematological malignancy*

In paragraph 8.3.3.1 is suggested that commonly used indicators for the quality of end-of-life care may not reflect how haematologists think what quality of end-of-life care entails for their patients. To develop a list of quality indicators for end-of-life care in patients with a haematological malignancy, a study with a Delphi technique can be useful. In such a study, haematologists with an interest for palliative care or a specialisation in palliative care can be asked to make a list of priorities regarding quality end-of-life care. Such a list of indicators of quality end-of-life care in haematology can subsequently be used in an evaluation study to find opportunities for improvement of proactive palliative care. A commonly used method for the evaluation of end-of-life care is a mortality follow-back design. The follow-back period can be three months for evaluating the terminal phase of the illness trajectory, or six months or one year for more upstream evaluation of the palliative phase of the illness trajectory.[19]

Early palliative care is preferable to timely prepare patients with a (potentially) life-threatening illness and their family. However, a proactive palliative care approach can also be initiated later in the illness trajectory, which is especially imaginable in patients with illness trajectories that are difficult to predict. Kripp et al. have constructed a prediction score for approaching death consisting of low performance status (ECOG score >2), low platelet count (<90×10−9/L), opioid treatment for pain (WHO level 3), high plasma LDH (>248U/L) and low plasma albumin (<30g/L).[96] Using these predictors, three risk groups can be identified: low risk (presence of no or one predictor; median survival of 440 days); intermediate risk (two or three predictors; median survival of 63 days); and high risk (median survival of 10 days). The Kripp prediction score can support identification of patients with palliative care needs and differentiate in urgency of their needs. However, this study was conducted in patients who were admitted to a palliative care unit, suggesting that these patients were already identified as having palliative care needs. Validation of the Kripp prediction score in a prospective cohort study in patients admitted to the haematology ward is needed to know whether the Kripp prediction score can be used to identify patients with approaching death.

### *2. Timely identification of palliative care needs: ED-triggered palliative care in patients with advanced cancer*

An ED-visit can be a trigger to initiate proactive palliative care.[65] In **Chapter 3** and **Chapter 4**, it seems that the ED-visit triggered discussions about limitations on life-sustaining treatments. A prospective cohort study in patients identified at the ED using the surprise question can provide insight into 1) whether ED-visits increase the number of documentation of goals-of-care discussions, and 2) goal concordance of care following the ED-visit.

The trigger card presented in **Chapter 3** included risk factors for approaching death in patients with advanced cancer. To validate the trigger card and to identify other predictors for approaching death, a prospective cohort study can be conducted in patients with a diagnosis of advanced cancer (without curative treatment options or with curative treatments with a substantial risk of mortality). ‘Death’ can be a candidate outcome measure to identify predictors for patients in the dying phase. However, ‘death within three months’ could be more clinically relevant in organising appropriate palliative terminal care at the place patients and their family would prefer.

**Chapter 5** demonstrated that patients with advanced cancer, about whom the clinician would not be surprised if they died within one year, and who have a poor physical performance (SQ plus ECOG 3-4), can be used to differentiate in the urgency of their needs. Research should be aimed at the question whether the use of SQ plus ECOG, as described in Table 3 in **Chapter 5**, improves patient outcomes such as quality of life and symptom burden. This could be studied in an ED using SQ plus ECOG to identify patients with palliative care needs in a prospective follow-up study design including questionnaires distributed to patients after 1, 3 and 6 months, and after 1 year. After identification in the ED, a multidimensional screening of problems should take place, for example by referring to the palliative care consultation team, or by screening by ED-clinicians using the 5-SPEED (see 8.5.2.2). As part of a cluster randomised trial, these outcomes can be compared with an ED in which standard care is provided. Also, SQ plus ECOG could be used to provide insight into the outcomes of ED-triggered palliative care as a care model. The outcomes of such a study can be a multidimensional approach to symptoms and the quality of palliative or end-of-life care including goal concordance.

The study in **Chapter 5** was conducted in patients who were already admitted to the ED. SQ plus ECOG could also provide insight if asked to the admitting clinician before admission to the ED. It could trigger goals-of-care discussions before ED-admission, which can contribute to appropriate care, with or without admission. This could be studied using a prospective cohort study design, in which the SQ plus ECOG could be asked to the ordering clinician during the triage process if it concerns a patient with advanced cancer. The primary outcome can be goal concordance of care, measured from data collected from patient records, for example by using the cues for documentation of proactive palliative care from 8.3.3.1.

It is known that conducting palliative care implementation research in the ED can be challenging. George et al. found that their screening tool was considered feasible in clinical practice by 70% of the ED-clinicians; however, although the 78% of patients who were found by screening as having unmet palliative care needs, only 26% was referred to palliative care.[97, 98] Successful implementation of a multidimensional screening intervention in the ED therefore depends on the quality of the implementation process. In Leiden University Medical Center's ED, the acutely presenting older patient (APOP) screener was carefully introduced in the workflow of this ED. The implementation strategy, which was part of a plan-do-study-act study, included acquiring information from clinicians and patients, adaptation of the screener where appropriate, development of standard operation procedures, integration into electronic patient records and an educational intervention, which all occurred pre-implementation. Already two months after implementation, 31% vs 21% ($p=0.0002$) received a comprehensive geriatric assessment.[99] This demonstrates that a plan-do-study-act strategy, which is part of participatory action research, can be an effective way to implement and study palliative care interventions in the ED.

### 8.4.3 Thinking ahead to be able to act before thing happen

*1. A two-track approach*

A two-track approach as described in **Chapter 4** and in paragraph 8.3.4.1 of this chapter can improve proactive care by concurrent tracks of curative care and palliative care. To develop a two-track model of care in a haematology department, a participatory action research (PAR) approach can be used. The development of a two-track model of care as a working method using PAR not only provides insight into how the model works in clinical practice, but also aims at implementing the model into daily care. It is therefore essential to make arrangements with all involved stakeholders, including the generalist palliative care responsibilities of haematology clinicians and the specialist palliative care responsibilities of palliative care consultants. These responsibilities are described by Henderson et al.[25] Additionally, haematology clinicians should be educated about generalist palliative care in the context of their responsibilities in the palliative care track.

The description of the two-track care model as a working method and how it can be implemented can support hospital wards to start working with a two-track care model. Using the quality indicators of paragraph 8.3.3.1, the quality of care can be evaluated before and after implementation of the two-track care model. The implementation should ideally be part of a cluster randomised trial, in which haematology wards of multiple hospitals are randomised to either standard care or the two-track care model. The primary outcome should be the quality of life, and potential secondary outcomes are multidimensional symptom burden, satisfaction with care and goal concordance of care.

The haematology palliative care model as described by Button (paragraph 8.3.3.1) assumes that all patients with a haematological malignancy need a palliative care approach because of the high mortality risk due to either the illness or the treatment.[58] The Button model is probably also appropriate in other illnesses that have a similar trajectory, for example aggressive but treatable carcinomas such as advanced stage melanomas, or osteosarcomas and pancreatic carcinomas that may be treated with surgery but may also have metastasized. Also non-cancer patients may have a 'haematology-like' trajectory, for example patients with serious infections acquiring intensive treatment and patients with organ failure waiting for transplantation. The aforementioned two-track care model could also be researched using PAR to develop and implement a working method for concurrent palliative care for these patients.

A two-track approach demands a proactive attitude in discussing palliative care needs. In **Chapters 3, 4 and 5**, cues for proactive palliative care were used to study the end-of-life trajectories of patients with advanced cancer or a haematological malignancy visiting the ED (see also paragraph 8.3.3.1). This list should be evaluated and complemented in a study among experts, for example by using a Delphi technique. The list with cues for proactive palliative care can be used in evaluation studies on the proactivity of palliative care, for example in a cohort study in patients identified as having palliative care needs.

*2. Discussing future scenarios*

The discussion of future scenarios is part of a two-track approach. **Chapter 6** has demonstrated that patients and family have information needs about symptoms and situations that are not actual yet. In **Chapter 7**, non-specialist palliative care clinicians indicated that the Leiden Guide on Palliative Care (LGP) included items that can support discussing and explaining future scenarios to patients and their family during palliative care conversations. To study if non-specialist clinicians feel supported in discussing future scenarios by using the LGP, a study can be conducted in two groups of clinicians: 1) those trained to use the LGP, and 2) those who were not trained to use the LGP. Both groups can be asked by using interviews or a questionnaire if they discuss future scenarios, and if they feel comfortable doing it. Also, for example one and six months after implementation, patient records can be searched for if discussed future scenarios are documented, and if the number of discussions is increased in the group that was trained in using the LGP.

## 8.5. RECOMMENDATIONS FOR EDUCATION, CLINICAL PRACTICE, AND POLICY

Recommendations for education, clinical practice, and policy following from this thesis will be addressed in three paragraphs:

1. Promoting knowledge and self-initiation in clinicians, and patients and family
2. Intention to produce good results and avoid (future) problems
3. Thinking ahead to be able to act before things happen

### 8.5.1 Promoting knowledge and self-initiation in clinicians, and patients and family

*1. Good education for undergraduate medical students*

Following the results from **Chapter 2**, addition of the five essential domains of end-of-life care education to the Dutch national blueprint on medical education was recommended. The study was one of the many efforts to improve undergraduate medical education on palliative care, including the PASEMECO and the O2PZ projects. With the revised blueprint published in 2020, generalist palliative care has become a compulsory part of the formal medical curricula in the Netherlands.

The PASEMECO toolbox and integral palliative care course are examples that can be useful for curriculum programmers and teachers to optimise the curricula.[27, 100] Among other aims (see 8.3.2.1), O2PZ is committed to supporting curriculum programmers in integrating palliative care into the packed medical curricula. In this way, palliative care education can be integrated in a way that suits the local curricula, and in coordination with curriculum programmers. It may be difficult to persuade curriculum programmers to make space for palliative care education. A suggestion to discuss with curriculum programmers is that all medical doctors should have generalist palliative care competences, because the palliative care demand will increase (see **Chapter 1**), and these generalist competences are described in the Quality framework on palliative care.[19, 20, 25]

Measuring and evaluating the quality of undergraduate medical education can result in better anchoring of palliative care in the curricula (see 8.4.1.1). Therefore, regular evaluation of undergraduate medical curricula is not only needed for research purposes, but also to guard the preparation of medical students for their future work, including generalist palliative care competences.

*2. Patient and family empowerment*

The Leiden Guide on Palliative Care (LGP), a palliative care conversation guide, combines assessment of symptom burden with assessment of information needs. Using feedback of patients, family and clinicians in **Chapter 7**, an instruction leaflet was developed (Supplement 7 of Chapter 7) in order to support clinicians in using the question prompt list appropriately and optimally. This instruction leaflet can be used in training and education about the empowerment of patients and family during individual conversations about palliative care. Good training in using the LGP is necessary since use of the question prompt list may evoke strong emotions in patients and family (**Chapter 7**), even though they expect to talk about difficult questions cohering to the phase of their illness.

**Chapter 6** demonstrated that symptom assessment alone is not sufficient to explore what topics patients worry about. It seems that patients and family want to know more about the future and how they can manage the illness themselves. From the results of this thesis follows that the LGP can be supportive in both assessing (information) needs, and providing person-centred advice appropriate for the phase of their illness. The use of a combination of a symptom assessment with a question prompt list in clinical practice is recommended.

A side outcome of this thesis is the uncertainty patients, family, lay people, but also clinicians, may experience about what palliative care actually entails. Appropriate and sufficient education of clinicians, patients and family is essential when reflecting on the core principles of proactive palliative care:

| Core principles of proactive palliative care |
|---|
| • Promoting knowledge and self-initiation in clinicians, patients, and family<br>• Intention to produce good results and avoid (future) problems<br>• Thinking ahead to be able to act before things happen |

This thesis only included studies relevant to individual palliative care consultations. To really improve proactivity in the triad patients, family and clinicians, community-based interventions should be initiated. When this thesis was being written, the SIRE (Stichting Ideële Reclame) initiated nation-wide advertisements about talking about death on television, radio, and the internet. References to websites and other sources supporting people to get more knowledgeable about palliative care are essential nowadays to reach people. Indeed, first knowledge should be promoted before self-initiation, intention to produce good results and avoid (future) problems, and thinking ahead to be able to act before things happen, can be achieved.

### 8.5.2 Intention to produce good results and avoid (future) problems

*1. Quality indicators for palliative care in patients with a haematological malignancy*

The concept of palliative care is often explained using the model of Lynn and Adams and the model of Murray (**Chapter 1**). These models assume that the palliative phase includes a phase with disease-modifying treatment and/or symptom-directed treatment, terminal phase, and bereavement care. There are in general three illness trajectories, namely advanced cancer, organ failure and frailty, and the multidimensional needs of patients and family can change along the illness trajectory. The illness trajectory of patients with a haematological malignancy does not fit these models. The model proposed by Button et al. is more appropriate for patients with a haematological malignancy (paragraph 8.3.3.1).[58] This model can be applicable not only for patients with a haematological malignancy, but also for patients with an unpredictable illness trajectory with a substantial risk of death because of either the illness or the treatment. The Button model should be part of generalist palliative care education since it raises awareness for a concurrent palliative care track while undergoing curative treatment.

In quality improvement projects, haematology specific quality indicators should be used. In 8.4.2 is discussed how a list of validated haematology quality indicators can be derived. In addition, in aiming at a proactive and person-centred care, the outcome of a quality improvement project can be the goal concordance of treatments with the wishes of patients and family.

### *2. Timely identification of palliative care needs: ED-triggered palliative care in patients with advanced cancer*

ED-visits can be a trigger for the initiation of palliative care and can improve the quality of life.[64, 66] Using the results in **Chapter 3**, and a report on care in the last phase of life in patients with advanced colon or lung cancer of by the Netherlands Care Institute (Zorginstituut Nederland), a trigger card was constructed that can support timely recognition of patients with advanced cancer at high risk of approaching death.[68] The trigger card supports taking directed actions in patients with urgent palliative care needs visiting the ED and can be implemented in the ED with help from a palliative care consultation team. Palliative care specialists should give instructions on how to use the trigger card, when to conduct goals-of-care discussions, and when to refer to specialist palliative care.

In **Chapter 4**, the predictive value of the surprise question (SQ) and the addition of other potential predictors for palliative care needs were studied. The SQ plus performance score of 3 or 4 according to the Eastern Cooperative Oncology Group (ECOG) can help differentiate in the urgency of palliative care needs in patients with advanced cancer. The clinical implications for using SQ plus ECOG 3-4 are summarised below (Table 1).

**Table 1.** Differentiating in urgency of palliative care needs in patients with advanced cancer visiting the emergency department, using the Surprise Question and functional status (using the ECOG classification), and appropriate actions

| Patients with advanced cancer | Median survival | Actions |
|---|---|---|
| **Step 1: Surprise Question** | | |
| NS | 3 months | Initiate symptom-management and focus care on quality of life |
| **Step 2: ECOG** | | |
| NS + ECOG 0-2; S | 6 months | Initiate a two-track approach by complementing disease-modifying treatment with conversations about the potential end of life and the patient’s wishes to prepare patients and family |
| NS + ECOG 3-4 | 1 month | Initiate end-of-life care according to the patient’s wishes as soon as possible |

Abbreviations: S: surprised; NS: not surprised; ECOG: Eastern Cooperative Oncology Group

After identification of patients who can benefit from a palliative care approach, they should be screened for symptoms or problems in a multidimensional way. George et al. developed a tool to screen for multidimensional palliative and end-of-life care needs in the ED, derived from a systematic review and shortened: 5-SPEED.[101, 102] (5-SPEED):[103]

1. pain management: how much are you suffering from pain?
2. home care: how much difficulty are you having getting your care needs met at home?
3. medication management: how much difficulty are you having with your medications?

4. psychological support: how much are you suffering from feeling overwhelmed?
5. goals of care: how much difficulty are you having getting medical care that fits with your goals?

Patients are instructed to score their answers to these questions on a 0-10 Likert scale. The 5-SPEED is validated for use in patients with cancer visiting the ED.[101]

### 8.5.3 Thinking ahead to be able to act before things happen

*1. A two-track approach*

In paragraph 8.4.2 is proposed that the Button illness trajectory model for patients with a haematological malignancy should be taught together with the more common used illness trajectories for patients with advanced cancer, organ failure and frailty. A two-track approach is a concrete application of the Button model. Education about the two-track approach in clinical practice can support non-specialist palliative care clinicians to discuss curative and palliative approaches to care with patients and their families. It is also possible to make arrangements with specialist palliative care clinicians, for example conducting the two-track approach together. In this case, the attending clinician can keep their role in the curative track, and the specialist palliative care clinician could be responsible for the palliative track. This may also help patients and family to bring up issues palliative care needs without having to worry that it will influence their curative treatment. It is important to note in education that initiating a palliative track is not only appropriate in patients who will certainly die soon; rather, patients with a possible life-threatening illness can have palliative care needs while undergoing intensive curative treatment. A two-track approach should be advertised as an approach that can answer the needs of these vulnerable patients.

*2. Discussing future scenarios*

Discussing future scenarios with patients and family is essential in providing proactive palliative care. However, current medical practice is mainly focused on the treatment of diseases (i.e., a more reactive approach). More attention should be invested in education and bedside teaching on prevention of unwanted outcomes, especially for clinicians providing generalist palliative care. A helpful model for initiating discussions about possible unfavourable outcomes in life-threatening illnesses and potentially curative treatments is the Goals of Car(e) model. Hui and Bruera used this model in an oncology clinic as part of integrated care. The Goals of Car(e) model uses a car as an analogy for the discussion of goals of care; not only the aspects of curative treatment, but also the aspects of supportive, palliative and hospice care should be discussed in order to prepare patients and family for a safe and pleasant road trip.[104]

Prevention can occur during individual consultations, but also on meso- and macro-level. The discussion about the prevention of unwanted outcomes can be initiated upfront, for example in healthy individuals: how do you wish your dying phase would look like, and what does absolutely not match how you want to die? Discussions about future scenarios can however take place at any time during an illness trajectory, since at any time unwanted outcomes can be prevented if discussed with patients and their family.

## CONCLUSION

Proactive palliative care includes three core principles: promotion of knowledge and self-initiation in the triad of clinician, patient, and family; the intention to produce good results and avoid (future) problems; thinking ahead to be able to act before things happen. This chapter outlined which opportunities for improving proactive palliative care are provided by this thesis: the need for quality palliative care education for clinicians, improvement of patient and family empowerment, quality indicators for end-of-life care, timely identification of palliative care needs, and a two-track approach for timely discussions about palliative care and future scenarios.

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