



Universiteit
Leiden
The Netherlands

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

Verhoef, M.J.

Citation

Verhoef, M. J. (2022, November 23). *Opportunities to improve palliative care: towards a more patient-centred and proactive approach*. Retrieved from <https://hdl.handle.net/1887/3486999>

Version: Publisher's Version

License: [Licence agreement concerning inclusion of doctoral thesis in the Institutional Repository of the University of Leiden](#)

Downloaded from: <https://hdl.handle.net/1887/3486999>

Note: To cite this publication please use the final published version (if applicable).



CHAPTER 9

Summary

This chapter includes a summary of the main findings presented in this thesis. A Dutch summary ('Nederlandse samenvatting') can be found in the Appendices.

CHAPTER 1. GENERAL INTRODUCTION

A palliative care approach aims to *"improve the quality of life of patients and their families facing the problem associated with a life-threatening illness or frailty, through the prevention and relief of suffering by means of early identification and impeccable assessment and treatment of pain and other problems, physical, psychosocial and spiritual."*¹ Palliative care should be integrated into standard care early in the trajectory of patients with a potential life-limiting illness to timely prepare them and their family on how to continue living their lives while the end of life may be near.² Integrated palliative care is associated with a better quality of end-of-life care compared to standard care alone.³⁻⁵ According to the 2018 Lancet Commission on Palliative Care and Pain Relief, serious health-related suffering will increase worldwide: in 2060, 47% of all people will die after going through serious health-related suffering.⁶ This underlines the importance of appropriate and timely initiation of palliative care.

In the Netherlands, palliative care is organised according to the generalist-specialist palliative care model.^{7,8} This means that every clinician working with patients should have basic knowledge and skills in providing palliative care, and that they can ask specialist palliative care clinicians for support in complex cases. It is therefore warranted that knowledge and skills are adequately provided and acquired during (medical) education. Previous Dutch evaluations have demonstrated that 30% of the medical doctors had insufficient knowledge about pain treatment, and that 83% of the medical doctors would appreciate additional education about opioid and pain treatment and about palliative sedation.^{9,10} Knowledge and skills regarding palliative care had not been assessed in detail yet in Dutch undergraduate medical students.

Generalist palliative care clinicians should be trained in identifying patients who can benefit from a palliative care approach. This includes the recognition of 'trigger moments', which are events that mark deterioration or increased need of palliative care. Recognition of 'trigger moments' allows clinicians to consider goals of care and to discuss these with patients and family.¹¹ An important example trigger moment is when patients with a potentially life-limiting illness visit the Emergency Department (ED): ED-triggered palliative care. It is known that patients who had received ED-triggered palliative care had a better quality of life than patients who received standard care.^{12,13}

The Surprise Question, “Would I be surprised if this patient died within one year?”, is used as an instrument to early identify patients with palliative care needs.¹⁴ Its use as a screening tool is recommended by the Netherlands Quality Framework for Palliative Care.² The prognostic value of the Surprise Question in the ED had already been studied in patients with heart failure and in elderly patients.^{15, 16} No studies had been conducted yet in patients with advanced cancer visiting the ED.

After identification of patients who may benefit from a palliative care approach, clinicians should assess which palliative care needs patients and their family have, in order to tailor palliative care. Comprehensive assessment includes multidimensional assessment of symptom burden and information needs. The Center of Expertise in Palliative Care of Leiden University Medical Center, the Netherlands, makes use of the Leiden Guide on Palliative Care (LGP) to guide their consultations with patients and family. The LGP exists of two parts. The first part comprises the Utrecht Symptom Diary, which is a translated and adapted Edmonton Symptom Assessment Scale.^{17, 18} The Utrecht Symptom Diary is used for measuring and monitoring symptom burden in the palliative phase on numeric rating scales of 1-10 of twelve symptoms that often occur in the palliative phase. The second part is a question prompt list on palliative care, a Dutch adaption of the version developed by Clayton et al.¹⁹ Patients and family can indicate in the question prompt list which topics and questions they wish to discuss during consultation. Patients and family who had used the question prompt list asked twice as many questions compared to those who had not.²⁰ Before conducting the studies included in this thesis, no Dutch question prompt list on palliative care had been evaluated. Moreover, the relationship between symptom burden and information needs, and what this could mean for initiating tailored conversations about palliative care, had not been studied before.

Appropriate education, insight into the use of trigger moments such as ED-visits, timely identification of patients in need of palliative care, and comprehensive assessment including assessment of symptom burden and information needs, are all key elements contributing to palliative care warranting a proactive approach. This thesis aims at identifying opportunities to improve patient-centred and proactive palliative care. 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 emergency department (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. END-OF-LIFE CARE IN THE DUTCH MEDICAL CURRICULA

This chapter describes a cross-sectional study assessing the extent to which end-of-life care was part of Dutch medical curricula. The focus on end-of-life care was chosen because it can be considered 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 scientific literature. The checklist was used to assess the Dutch national blueprint on medical education²¹ and the Dutch medical curricula of the eight medical faculties in the Netherlands. The assessed education included eight bachelor studies, eight master studies and elective courses. Study coordinators of bachelor and master curricula were approached to fill out a questionnaire derived from the checklist and were interviewed afterwards to acquire explanation on their answers in the questionnaire. The study guides of all medical faculties were used to assess the electives. The blueprint included four of the five domains of end-of-life care. None of the eight medical faculties taught all domains specifically on end-of-life care. Most attention was given to psychological, sociological, cultural and spiritual aspects; communication and conversational techniques; and juridical and ethical aspects. One faculty taught an elective course that included all essential aspects of the international standards. We concluded that to improve education on end-of-life care, the five essential domains should be added to the Dutch national blueprint on medical education, which was due for revision in 2019. Additionally, medical faculties should review their curricula and offer end-of-life care as compulsory part of the medical curricula to prepare medical students for their future medical practice.

CHAPTER 3. PALLIATIVE CARE NEEDS OF ADVANCED CANCER PATIENTS IN THE EMERGENCY DEPARTMENT AT THE END OF LIFE: AN OBSERVATIONAL COHORT STUDY

Insight in the end-of-life trajectories of patients with advanced cancer visiting the Emergency Department (ED) is of added value in the context of ED-triggered palliative care. Chapter 3 describes a mortality follow-back study in 420 patients with advanced cancer who visited the ED up to three months before they died. This study showed that patients with advanced cancer often visited the ED while their care was 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, hypercalcaemia, and jaundice. We concluded that timely recognition of patients at high risk of approaching death can improve end-of-life care in patients with advanced cancer. To facilitate timely recognition, a flowchart was constructed which supports taking directed actions in patients with advanced cancer and urgent palliative care needs in the ED.

CHAPTER 4. END-OF-LIFE TRAJECTORIES OF PATIENTS WITH HAEMATOLOGICAL MALIGNANCIES AND PATIENTS WITH ADVANCED SOLID TUMOURS VISITING THE EMERGENCY DEPARTMENT: THE NEED FOR A PROACTIVE INTEGRATED CARE APPROACH

ED-triggered palliative care can avoid potentially inappropriate end-of-life care.^{12, 13} Patients with a haematological malignancy more frequently receive aggressive end-of-life care than patients with a solid tumour.²² 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. The aim was to compare the end-of-life trajectories and quality of end-of-life care between these patients using five of Earl et al.'s quality indicators of end-of-life care: intensive anticancer treatment <3 months, ED visits <6 months, in-hospital death, death in the intensive care unit (ICU), and in-hospice death. Cues for proactive care were 1) communication about the patient's condition between a hospital clinician or palliative care consultation team and the patient's general practitioner; 2) proactive care plans; 3) and limitations on life-sustaining treatments before the current ED-visit. Before their ED-visits, patients with a haematological malignancy had less frequently discussed limitations on life-sustaining treatments than patients with a solid tumour. Since their ED-visit, patients with a haematological malignancy

received more aggressive end-of-life care and were more frequently hospitalized after their ED-visit. They died more frequently in-hospital, in the intensive care unit or in the ED. To aid both patients and ED-staff, we recommend implementing a two-track approach, a care model for early integration of palliative care concurrent with curative haematological treatment. The two-track approach aims at preparing patients with a haematological malignancy for death as a possible outcome of either their life-threatening disease or heavy treatment in a timely matter, when they can still express their wishes.

CHAPTER 5. SURPRISE QUESTION AND PERFORMANCE STATUS INDICATE URGENCY OF PALLIATIVE CARE NEEDS IN PATIENTS WITH ADVANCED CANCER AT THE EMERGENCY DEPARTMENT: AN OBSERVATIONAL COHORT STUDY

The Surprise Question (SQ), “Would I be surprised if this patient died within one year?”, is an instrument to identify patients with palliative care needs.¹⁴ The SQ is asked and answered by the clinician. An “not surprised” (NS)-answer is indicative for potential palliative care needs, which should be further assessed. A meta-analysis by Downar et al. demonstrated that SQ may not be a sufficient screening tool for death within one year in the overall population of patients with advanced cancer.²³ It lacked sensitivity and, therefore, under-estimated the number of patients with palliative care needs. The SQ may be more accurate combined with other indicators of palliative care needs, such as symptoms prevalent in the palliative phase, performance status, and indicators of increased utilization of formal and informal care. Chapter 5 includes an observational cohort study in 245 patients with advanced cancer visiting the ED in 2013 and 2014 to evaluate the test characteristics of the SQ. The addition of other clinical factors predictive of death was studied to find if these can improve the SQ’s test performance. The results show that 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%). Performance status can be a valuable addition to the SQ to differentiate in prognosis and thus in urgency of palliative care needs. In the ED, the combination of first, the SQ, and second, performance status, can function as a trigger to start palliative care according to patient’s wishes. A model including the SQ and performance score was constructed to support which actions are appropriate for which urgency of palliative care needs in patients with advanced cancer visiting the ED.

CHAPTER 6. ASSESSMENT OF PATIENT SYMPTOM BURDEN AND INFORMATION NEEDS HELPS TAILORING PALLIATIVE CARE CONSULTATIONS: AN OBSERVATIONAL STUDY

We performed an observational study in 321 patients referred to a palliative care consultation team who had used a LGP between 2013 and 2018 to provide insight into the relationship between patient-reported symptom burden and information needs (Chapter 6). The secondary aim was to study the relationship between palliative phase (disease-modifying versus symptom-management), and symptom burden and information needs. Most patients in this study had a diagnosis of cancer. Patients reported highest median symptom burden for *Fatigue* and *Less appetite*. Most information needs were about *Fatigue*, *Possibilities for managing complaints in the future* and *Complaints expected for the future*. Patients had 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 they wanted information about that symptom. Patients in the symptom-management phase more often wanted information about how they could manage care at home or in a hospice, while patients in the disease-modifying phase wanted more information about how treatment could affect their quality of life. This study showed that assessment of symptom burden alone is not sufficient to explore about which topics patients need more information or about which they worry.

CHAPTER 7. NON-SPECIALIST PALLIATIVE CARE - QUESTION PROMPT LIST PREPARATION: PATIENT, FAMILY AND CLINICIAN EXPERIENCES.

Chapter 7 is a mixed-methods study performed in 2017-2018 to evaluate the use of the question prompt list of the LGP and to further develop it. Using 35 interviews (18 with patients and family, and 17 with clinicians), the use of the question prompt list was evaluated. The question prompt list was further developed using their suggestions. Thirty-two consultations were audiotaped and transcribed to explore the extent to which topics that patients and family had indicated to discuss, were actually discussed during the consultation. The results show that patients, family and clinicians regarded the question prompt list as relevant, comprehensible and comprehensive. 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 described 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 that patients and family had indicated were discussed frequently, but also topics aimed at (re)organising life at home were discussed. Using feedback of patients, family and clinicians, the LGP was adapted and an instruction leaflet was written in order to support clinicians in using the question prompt list appropriately and optimally.

CHAPTER 8. GENERAL DISCUSSION

Chapter 8 comprises five parts. In part 1, the studies included in this thesis are summarized. Part 2 reflects on the study methods that were used. In part 3, the implication of the findings is presented using the concept of proactive palliative care. Using the definitions for 'proactivity' and 'palliative care', three core principles of proactive palliative care can be identified:

- promotion of knowledge and self-initiation in the triad of patient, family and clinician;
- the intention to produce good results and avoid (future) problems;
- thinking ahead to be able to act before things happen.

This thesis describes how knowledge and self-initiation of the triad patients, their family and clinicians can be promoted. Medical students should be provided sufficient education to prepare them for their clinical practice, which includes patients in the last phase of their lives. Conversation guides such as the Leiden Guide on Palliative Care empower patients and family, which contributes to their knowledge and self-initiation.

To have the intention to produce good results and avoid (future) problems, clinicians should have knowledge about what cues and indicators for good quality and proactive palliative care are. Indicators for quality and proactive palliative care are illustrated using the example of patients with a haematological malignancy. Quality and proactive palliative care include early identification of patients visiting the Emergency Department (ED). An ED-visit can be a trigger to discuss goals of care and recognition of this trigger-function supports appropriate care.

Using a two-track approach and discussing future scenarios are key components in 'thinking ahead to be able to act before things happen'. Person-centred communication methods and conversation guides can support using a two-track approach and discussing future scenarios.

The chapter further provides, from the core principles of proactive palliative care, a number of recommendations for further research (part 4) and for education, clinical practice, and policy (part 5).

REFERENCES

1. World Health Organization Definition of Palliative Care, <http://www.who.int/cancer/palliative/definition/en/> (accessed 05-10-2018).
2. Integraal Kankercentrum Nederland (IKNL)/Palliatief. Netherlands Quality Framework for Palliative Care. 2017.
3. Temel JS, Greer JA, Muzikansky A, et al. Early palliative care for patients with metastatic non-small-cell lung cancer. *The New England Journal of Medicine* 2010; 363: 733-742. DOI: 10.1056/NEJMoa1000678.
4. Hui D, Kim SH, Roquemoire J, et al. Impact of timing and setting of palliative care referral on quality of end-of-life care in cancer patients. *Cancer* 2014; 120: 1743-1749. 2014/06/27.
5. Maltoni M, Scarpi E, Dall'Agata M, et al. Systematic versus on-demand early palliative care: A randomised clinical trial assessing quality of care and treatment aggressiveness near the end of life. *Eur J Cancer* 2016; 69: 110-118. 2016/11/09. DOI: 10.1016/j.ejca.2016.10.004.
6. Sleeman KE, de Brito M, Etkind S, et al. The escalating global burden of serious health-related suffering: projections to 2060 by world regions, age groups, and health conditions. *Lancet Glob Health* 2019; 7: e883-e892. 2019/05/28. DOI: 10.1016/S2214-109X(19)30172-X.
7. Quill TE and Abernethy AP. Generalist plus specialist palliative care--creating a more sustainable model. *N Engl J Med* 2013; 368: 1173-1175. 2013/03/08. DOI: 10.1056/NEJMp1215620.
8. Henderson JD, Boyle A, Herx L, et al. Staffing a Specialist Palliative Care Service, a Team-Based Approach: Expert Consensus White Paper. *J Palliat Med* 2019; 22: 1318-1323. 2019/07/28. DOI: 10.1089/jpm.2019.0314.
9. Integraal Kankercentrum Nederland (IKNL). Palliatieve zorg in Beeld. 2014.
10. Rurup ML, Rhodius CA, Borgsteede SD, et al. The use of opioids at the end of life: the knowledge level of Dutch physicians as a potential barrier to effective pain management. *BMC Palliat Care* 2010; 9: 23. 2010/11/16. DOI: 10.1186/1472-684X-9-23.
11. Haydar SA, Almeder L, Michalakos L, et al. Using the Surprise Question To Identify Those with Unmet Palliative Care Needs in Emergency and Inpatient Settings: What Do Clinicians Think? *J Palliat Med* 2017; 20: 729-735. 2017/04/25. DOI: 10.1089/jpm.2016.0403.
12. Grudzen CR, Richardson LD, Johnson PN, et al. Emergency Department-Initiated Palliative Care in Advanced Cancer: A Randomized Clinical Trial. *JAMA Oncol* 2016 2016/01/16. DOI: 10.1001/jamaoncol.2015.5252.
13. Grudzen CR, Stone SC and Morrison RS. The palliative care model for emergency department patients with advanced illness. *J Palliat Med* 2011; 14: 945-950. 2011/07/20. DOI: 10.1089/jpm.2011.0011.
14. Pattison M and Romer AL. Improving Care Through the End of Life: launching a primary care clinic-based program. *J Palliat Med* 2001; 4: 249-254. 2001/07/10. DOI: 10.1089/109662101750290335.
15. Aaronson E, George N, Ouchi K, et al. The Surprise Question Can Be Used to Identify Heart Failure Patients in the Emergency Department Who Would Benefit from Palliative Care. *J Pain Symptom Manage* 2019 2019/02/19. DOI: 10.1016/j.jpainsymman.2019.02.007.
16. Ouchi K, Jambaulikar G, George NR, et al. The "Surprise Question" Asked of Emergency Physicians May Predict 12-Month Mortality among Older Emergency Department Patients. *J Palliat Med* 2018; 21: 236-240. 2017/08/29. DOI: 10.1089/jpm.2017.0192.
17. van der Baan FH, Koldenhof JJ, de Nijs EJ, et al. Validation of the Dutch version of the Edmonton Symptom Assessment System. *Cancer Med* 2020 2020/07/10. DOI: 10.1002/cam4.3253.

18. Bruera E, Kuehn N, Miller MJ, et al. The Edmonton Symptom Assessment System (ESAS): a simple method for the assessment of palliative care patients. *J Palliat Care* 1991; 7: 6-9. 1991/01/01.
19. Clayton J, Butow P, Tattersall M, et al. Asking questions can help: development and preliminary evaluation of a question prompt list for palliative care patients. *Br J Cancer* 2003; 89: 2069-2077. 2003/12/04. DOI: 10.1038/sj.bjc.6601380.
20. Clayton JM, Butow PN, Tattersall MH, et al. Randomized controlled trial of a prompt list to help advanced cancer patients and their caregivers to ask questions about prognosis and end-of-life care. *J Clin Oncol* 2007; 25: 715-723. 2007/02/20. DOI: 10.1200/jco.2006.06.7827.
21. van Herwaarden CLA, Laan R and Leunissen RRM. Raamplan Artsenopleiding 2009. Nederlandse Federatie van Universitair Medische Centra, 2009.
22. Hui D, Didwaniya N, Vidal M, et al. Quality of end-of-life care in patients with hematologic malignancies: a retrospective cohort study. *Cancer* 2014; 120: 1572-1578. 2014/02/20. DOI: 10.1002/cncr.28614.
23. Downar J, Goldman R, Pinto R, et al. The "surprise question" for predicting death in seriously ill patients: a systematic review and meta-analysis. *CMAJ* 2017; 189: E484-E493. 2017/04/08. DOI: 10.1503/cmaj.160775.